

# Cerebrovascular Disease Supplement 2: Disclosure of Interests Forms of the Guideline Panel

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# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces,

markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No
- Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>

### Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don't know
- No
- Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

- Don't know
- No
- Yes

If yes, please explain:



6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

### Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution? I am not sure of this I would hope that I would receive great support from the panel mentor.

### Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain:

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>

# Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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## Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 3/6/17; Panepinto 3/8/17; Kunkle 1/23/18	No	No	
Webb 4/16/19	No	No	On April 5, 2019, Ms. Barber confirmed all information in this form.

## Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

## Other Notes

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# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

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No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

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Column 1 Name the company.

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Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
DeBaun and Alsup	Medical expert consultation	Present	Not a conflict. Dr. DeBaun explained that the company reviews medical malpractice claims that are not specific to sickle cell disease.

## My Partner's or Spouse's Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
DeBaun and Alsup	Paperwork for medical expert consultation	Present	Not a conflict. As described above, the company is not expected to be affected by these guidelines.

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

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No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

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Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

Evidence should drive the decisions, when evidence is available.

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made? See CV.

**I have been invited to 37 major lectures on sickle cell from 1995-2014, for example:**

DeBaun MR. *From Classroom Observation to an International Clinical Trial: Significance and Optimal Treatment of Silent Strokes in Students with Sickle Cell Disease*. 56<sup>th</sup> ASH Annual Meeting and Exposition San Francisco, CA, December 8, 2014

**I have been invited to 8 Professorships from 2006-2015, for example:**

DeBaun MR. *Overt and Silent Strokes in Sickle Cell Disease: When is Blood Transfusion Therapy no longer Good Enough?* Louis & Bertie Cohen Memorial Lecture. Pediatric Grand Rounds; The

Children's Hospital of Philadelphia. April 2015.

**I have 50 publications related to sickle cell disease and the brain from 1993-2016, for example:**

1. Hulbert ML, McKinstry RC, Lacey JI, Moran CJ, Panepinto JA, Thompson AA, Sarnaik SA, Woods GM, Casella JF, Inusa B, Howard J, Kirkham FJ, Anie KA, Mullin JE, Ichord R, Noetzel M, Yan Y, Rodeghier M, **DeBaun MR**. Silent cerebral infarcts occur despite regular blood transfusion therapy after first strokes in children with sickle cell disease. *Blood*. 2011 Jan; 117(3):772-779. PMID: 20940417, PMC3035071.
2. Savage WJ, Barron-Casella E, Fu Z, Dulloor P, Williams L, Crain BJ, White DA, Jennings JM, Van Eyk JE, **DeBaun MR**, Everett A, Casella JF. Plasma glial fibrillary acidic protein levels in children with sickle cell disease. *Am J Hematol*. 2011 May; 86(5): 427-429. PMID: 21523806, PMC3870012.
3. **DeBaun MR**, Sarnaik SA, Rodeghier MJ, Minniti CP, Howard TH, Iyer RV, Inusa B, Telfer PT, Kirby-Allen M, Quinn CT, Bernaudin F, Airewele G, Woods GM, Panepinto JA, Fuh B, Kwiatkowski JK, King AA, Rhodes MM, Thompson AA, Heiny ME, Redding-Lallinger RC, Kirkham FJ, Sabio H, Gonzalez CE, Saccente SL, Kalinyak KA, Strouse JJ, Fixler JM, Gordon MO, Miller JP, Ichord RN, and Casella JF. Associated risk factors for silent cerebral infarcts in sickle cell anemia: low baseline hemoglobin, gender and relative high systolic blood pressure. *Blood*. 2012 Apr; 119(16):3684-3690. PMID: 22096242, PMC3335377.
4. Mullin JE, Cooper BP, Kirkham FJ, Rosen CL, Strunk RC, **DeBaun MR**, Redline S, Kemp JS. Stability of polysomnography for one year and longer in children with sickle cell disease. *J Clin Sleep Med*. 2012 Oct 15; 8(5):535-539. PMID: 23066365, PMC3459199.
5. Thangarah M, Yang G, Fuchs D, Ponisio M, McKinstry R, Jaju A, Noetzel M, Casella J, Barron-Casella R, Hopper W, Boulet S, Bean C, Pyle M, Payne A, Driggers J, Trau H, Vendt B, Rodeghier M, **DeBaun M**. Magnetic resonance angiography-defined intracranial vasculopathy is associated with silent cerebral infarcts and glucose-6-phosphate dehydrogenase mutation in children with sickle cell anaemia. *British Journal of Haematology*. 2012 Sept; 159(3):352-359. PMID: 22958163, PMC3775590.
6. Liem RI, Liu J, Gordon MO, Vendt BA, McKinstry MC, Kraut MA, Strouse JJ, Ball WS, **DeBaun MR**. Reproducibility of detecting silent cerebral infarcts in pediatric sickle cell anemia. *J Child Neurol*. Dec;29(12):1685-91.PMID: 24309240, PMC4096057.
7. Quinn CT, McKinstry RC, Dowling MM, Ball WS, Kraut MA, Casella JF, Dlamini N, Ichord RN, Jordan LC, Kirkham FJ, Noetzel MJ, Roach ES, Strouse JJ, Kwiatkowski JL, Hirtz D, **DeBaun MR**. Acute silent cerebral ischemic events in children with sickle cell anemia. *JAMA Neurol*. 2013 Jan; 70(1):58-65. PMID: 23108767, PMC3677221.
8. Falcon LM, Fu Z, Dulloor P, Barron-Casella E, Savage W, Jennings JM, Van Eyk JE, **DeBaun M**, Casella JF, Everett A. Thrombospondin-1 and L-selectin are associated with silent cerebral infarct in children with sickle cell anaemia. *Br J Haematol*. 2013 Aug; 162(3):421-424. PMID: 23672305, PMC4391368.
9. Dowling MM, Noetzel MJ, Rodeghier MJ, Quinn CT, Hirtz DG, Ichord RN, Kwiatkowski JL, Roach ES, Kirkham FJ, Casella JF, **DeBaun MR**. Headache and migraine in children with sickle cell disease

are associated with lower hemoglobin and higher pain event rates but not silent cerebral infarction. *J Pediatr*. 2014 May;164(5):1175-1180.e1. PMID: 24529619, PMC4078657.

10. Roberts DO, Covert B, Rodeghier MJ, Parmar N, **DeBaun MR**, Thompson AA, Liem RI. Randomization is not associated with socio-economic and demographic factors in a multi-center clinical trial of children with sickle cell anemia. *Pediatr Blood Cancer*. 2014 Sep;61(9):1529-35. Apr 22. PMID: 24753128, PMC4107131.
11. **DeBaun MR**, Gordon M, McKinstry RC, Noetzel MJ, White DA, Sarnaik SA, Meier ER, Howard TH, Majumdar S, Inusa BP, Telfer PT, Kirby-Allen M, McCavit TL, Kamdem A, Airewele G, Woods GM, Berman B, Panepinto JA, Fuh BR, Kwiatkowski JL, King AA, Fixler JM, Rhodes MM, Thompson AA, Heiny ME, Redding-Lallinger RC, Kirkham FJ, Dixon N, Gonzalez CE, Kalinyak KA, Quinn CT, Strouse JJ, Miller JP, Lehmann H, Kraut MA, Ball WS Jr, Hirtz D, Casella JF. Controlled trial of transfusions for silent cerebral infarcts in sickle cell anemia. *NEJM*. 2014 Aug 21;371(8):699-710. PMID: 25140956, PMID: 25140956, PMC4195437.
12. Galadanci NA, Abdullahi SU, Tabari MA, Abubakar S, Belonwu R, Salihu A, Neville K, Kirkham F, Inusa B, Shyr Y, Phillips S, Kassim AA, Jordan LC, Aliyu MH, Covert BV, **DeBaun MR**. Primary stroke prevention in Nigerian children with sickle cell disease (SPIN): Challenges of conducting a feasibility trial. *Pediatr Blood Cancer*. 2014 Nov 14. pbc.25289. PMID: 25399822, PMC4304992.
13. **DeBaun MR**, Casella JF. Transfusions for silent cerebral infarcts in sickle cell anemia. *N Engl J Med*. 2014 Nov 6;371(19):1841-2. NEJM c1411133. PMID: 25372094.
14. Andreotti C, King AA, Macy E, Compas BE, **DeBaun MR**. The association of cytokine levels with cognitive function in children with sickle cell disease and normal MRI studies of the brain. *J Child Neurol*. 2015 Sep;30(10):1349-53. PMID: 25512362, PMC4466214.
15. Kassim AA, Galadanci NA, Pruthi S, **DeBaun MR**. How I treat acute strokes and long-term management in sickle cell disease. *Blood*. May 28;125(22):3401-10. PMID: 25824688, PMC4467906.
16. Konopka JA, **DeBaun MR**, Chang W, Dragoo JL. The Intracellular Effect of Relaxin on Female Anterior Cruciate Ligament Cells. *Am J Sports Med*. 2016 May 31. pii: 0363546516646374. PMID: 27245459
17. Sanger M, Jordan L, Pruthi S, Day M, Covert B, Merriweather B, Rodeghier M, **DeBaun M**, Kassim A. Cognitive deficits are associated with unemployment in adults with sickle cell anemia. *J Clin Exp Neuropsychol*. 2016 Aug;38(6):661-71. doi: 10.1080/13803395.2016.1149153. PMID: 27167865
18. Silent cerebral infarcts and cerebral aneurysms are prevalent in adults with sickle cell anemia. Kassim AA, Pruthi S, Day M, Rodeghier M, Gindville MC, Brodsky MA, **DeBaun MR**, Jordan LC *Blood*. 2016 Mar 3. pii: blood-2016-01-694562. [Epub ahead of print] No abstract available. PMID: 26941400

**I have 42 invited peer reviewed publications, editorial, book chapter or electronic chapters from 1998-2016, for example:**

1. **DeBaun MR**, Kirkham FJ. Central nervous system complications and management in sickle cell disease. *Blood*. 2016 Feb 18;127(7):829-38. doi: 10.1182/blood-2015-09-618579. Epub 2016 Jan 12. Review. PMID: 26758917
2. **DeBaun MR**, Kirkham FJ. New option for primary stroke prevention in sickle cell anaemia. *Lancet*. 2016 Feb 13;387(10019):626-7. doi: 10.1016/S0140-6736(15)01130-7. Epub 2015 Dec 6. No abstract available.
3. Jordan LC, Casella JF, DeBaun MR. Prospects for primary stroke prevention in children with sickle cell anaemia. *Br J Haematol*. 2012 Apr; 157(1):14-25. PMID: 22224940, PMC3400704.
4. **DeBaun MR**, Armstrong FD, McKinstry RC, Ware RE, Vichinsky E, Kirkham FJ. Silent cerebral infarcts: a review on a prevalent and progressive cause of neurologic injury in sickle cell anemia. *Blood*. 2012 May; 119(20): 4587-4596. PMID: 22354000, PMC3367871.
5. Lebensburger JD, **DeBaun MR**, Thompson AA. What is the evidence for using hydroxyurea for secondary stroke prevention? *Hematology Am Soc Hematol Educ Program*. 2011 Dec; 2011:440-2. PMID: 22160071.
6. **DeBaun MR**. Secondary prevention of overt strokes in sickle cell disease: therapeutic strategies and efficacy. *Hematology Am Soc Hematol Educ Program*. 2011 Dec; 2011: 427-433. PMID: 22160069

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No
- Yes, as described below: see CV for complete listing.

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>
NINDS	Primary prevention of stroke in children with	PI	7/2020

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>
	SCD in Sub-Saharan Africa II		
NIH/NCATS	The major goals of VICTR are removing impediments to research translation, creating new infrastructure, training new C&T scientists, and engaging and involving the local community to improve health.	Associate PD CRRF and Peds Director	1/2018
NIH/NCATS	Improving Clinical trial Education, Recruitment, and Enrollment at CTSA Hubs (I-CERCH)	Co-investigator	6/2021
NIH/NHLBI	Cellular and Molecular Mechanisms of Acute Lung Injury in Sickle Cell Disease	PI	5/2018
PCORI	The Mid-South CDRN Phase II	Co-Investigator	9/2018
PCORI	Tennessee Sickle Cell Disease Network	Co-Investigator	12/2016
American Heart Association	MRI-based quantitative brain oxygen metabolism mapping in sickle cell anemia	Collaborator	6/2017
NIH/NICHD	Pathogenesis, Targeted Therapeutics, and New Vaccines for Childhood Disease	Training Director/Mentor	11/2020
Burroughs Wellcome Foundation	Cysteinyl Leukotrienes Receptor Inhibitors: A Target for Decreasing Sickle Cell Disease-Related Morbidity	PI	12/2016
Junior League of Nashville	Sickle Cell and Asthma Center at Matthew Walker	PI	6/2017

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>
Thrasher Research Fund	Al Thrasher Award Hydroxyurea for Secondary Stroke Prevention in Children with Sickle Cell Disease in sub-Saharan Africa	PI	6/2019
Doris Duke Charitable Foundation	The Clinical and Translational Research Training Center in Northern Nigeria	PI	12/2015

## Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

Don't know

No

Yes

If yes, please explain:

No, my current salary is fixed.

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

Don't know

No

Yes

If yes, please explain:

Patient care and research fund part of my salary.

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

## Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

No career advancement

## Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

Professor of Pediatrics and Medicine, Board certified pediatrician, pediatric hematologist and oncologist



If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain:

Blood transfusion therapy for primary and secondary prevention of strokes and silent cerebral infarcts

### Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
n/a	Member, Advisory Counsel of the National Heart, Lung, and Blood Institute	1/17/18	Not a conflict. NHLBI is not an affected company.

# Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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## Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 9/13/16; Kunkle 9/13/16;	No	No	
Webb 1/17/18; Kunkle 1/23/18; Panepinto 1/24/18	No	No	New disclosure, not a conflict. See Part D above. Added "Other Notes" below.
Webb Panepinto 6/9/2019	No	No	Other notes added below. On June 28, 2019 Dr. DeBaun confirmed all information in this form.

## Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

## Other Notes

Dr. DeBaun is a pediatric hematologist and oncologist who sees and treats patients with SCD. In his clinical practice, he uses transfusion for primary and secondary prevention of strokes and silent cerebral infarcts in patients with SCD. He is or was recently the principal investigator on research projects relevant to these guidelines, including a study on the primary prevention of stroke in children

with SCD in Sub-Saharan Africa, funded by the National Institute of Neurological Disorders and Stroke, and a study on hydroxyurea for secondary stroke prevention in children with SCD in Sub-Saharan Africa, funded by the Thrasher Research Fund. He is or was recently an investigator on other research projects about SCD funded by the Patient-Centered Outcomes Research Initiative, the American Heart Association, the Burroughs Wellcome Foundation, and the Junior League of Nashville. Dr. DeBaun has lectured about SCD and has authored multiple reports of original research, reviews, opinion articles and editorials, and book chapters about cerebrovascular complications of SCD, including screening for stroke and prevention and treatment of stroke. Dr. DeBaun has two new research awards. He is the principal investigator on a National Institutes of Health/National Heart Lung and Blood Institute (NIH/NHLBI) study related to cerebral infarcts and sickle cell anemia; and a principal investigator for the cure sickle cell initiative data coordinating center sponsored by NIH/NHLBI.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

## Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>
UpToDate	Co-author, 3 UpToDate topics: Ischemic stroke in children and young adults: Etiology and clinical features; Ischemic stroke in children: Evaluation, initial management, and prognosis; Ischemic stroke in children: Secondary prevention	Ongoing co-author for pediatric stroke topics but only received royalties from 2014-2016	Not a conflict. UpToDate is a medical publisher. It does not market any products that could be affected by these guidelines.

## Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces,



markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain: Clinical practice guidelines should be evidence-based.

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

Speaker, International Sickle Cell Disease Workshop, Children's Hospital Oakland Research Institute, 2012 and 2013; Topic: Brain Injury in Sickle Cell Disease.

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No
- Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>

### Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don't know
- No
- Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

- Don't know

No

Yes

If yes, please explain:

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

### Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

My Division Chief, Department Chair and Institution would remain supportive of my position.

### Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

- No  
 Yes

If yes, what is your primary specialty or subspecialty?

Pediatric stroke; I am board certified in Vascular Neurology and Child Neurology.

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

- No  
 Yes

If yes, please explain:

Within my practice, I treat patients with cerebrovascular complications of sickle cell disease. As part of my clinical practice, I recommend screening and diagnostic tests, treatments and procedures that may be addressed by these guidelines (for example, TCD, MRI/MRA, transfusion).

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

- No  
 Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
UpToDate	Continue to receive royalties as Co-author for UpToDate topics.	4/8/19	Not a conflict. See above.

## Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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### Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 2/23/17; Panepinto 3/4/17; Kunkle 1/22/18	No	No	
Webb 4/16/19	No	No	On April 8, 2019, Dr. Fox confirmed all information in this form.

### Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

### Other Notes

As a specialist in vascular neurology, Dr. Fox treats patients with cerebrovascular complications of SCD, including by recommending screening and diagnostic tests such as TCD and MRI and treatments such as transfusion. She has given educational talks on brain injury in SCD and has authored articles published by UpToDate on stroke in children and young adults.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.



<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces,

markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

Writing a review article now on stroke and neuroimaging in sickle cell disease for the Journal of Cerebral Blood Flow and Metabolism. Evidence-based and peer reviewed.

I have published articles on PubMed on stroke in sickle cell disease (original research, peer reviewed).

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No
- Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>
NIH	MRI study of cerebral hemodynamics in young adults with SCD (for markers that increase the risk of stroke)	PI	6/30/2018
American Heart Association	MRI study of cerebral hemodynamics in children with SCD (for markers that increase the risk of stroke)	PI	2/28/2021

### Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don't know
- No
- Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

Don't know

No

Yes

If yes, please explain:

I see children with strokes in clinic (I direct the pediatric stroke program at Vanderbilt) and some of these children have SCD. No income other than routine clinical billing for seeing patients.

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

## Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

I would be supported as long as guidelines are evidence based, and I am sure they will be.

## Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

Pediatric Neurology – pediatric stroke specialist.

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain: I order MRIs on children with SCD if there are concerns for stroke.

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:



## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>

## Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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### Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 3/2/17; Panepinto 3/5/17; Kunkle 1/23/18; Panepinto 1/24/18	No	No	
Webb 4/17/19	No	No	On April 17, 2019, Dr. Jordan confirmed all information in this form.

### Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

### Other Notes

Dr. Jordan is a pediatric stroke specialist and the director of the pediatric stroke program at her institution. In her clinical practice, she orders MRIs on children with SCD. She is the principal investigator on MRI studies of cerebral hemodynamics in children and young adults with SCD (for markers that increase the risk of stroke), funded by the National Institutes of Health and by the American Heart Association. She has authored reviews on stroke and neuroimaging in SCD as well as reports of original research on this topic.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>
Magenta Therapeutics	Own \$200 in shares, (husband helped found)		Indirect conflict. Magenta Therapeutics is developing gene and cell technologies and therapeutics, including for use in stem cell transplantation for SCD. Although these guidelines will not address stem cell transplantation, the company could be indirectly affected by recommendations that explicitly or implicitly suggest there is a need for curative therapies for SCD.

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

## Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
Magenta Therapeutics	Own stock	ongoing	Indirect conflict. As described above, Magenta Therapeutics could be indirectly affected by these guidelines. Dr. King's husband is a cofounder of the company.
Celgene	Consulting	ongoing	Indirect conflict. In 2016, Celgene acquired Acetylon. Acetylon is in the preclinical phase of developing a potentially disease-modifying therapy for SCD. The therapy is not yet to market and will not be specifically addressed in these guidelines; however, the company could be indirectly affected by recommendations that explicitly or implicitly suggest there is a need for curative therapies for SCD.
Bioline	Consulting	ongoing	Indirect conflict. Bioline is researching technologies applicable to gene and cell therapies. As above, the company could be indirectly affected by recommendations of these guidelines.
Vasculox (Tioma Therapeutics)	Consulting	ongoing	Not a conflict. Tioma Therapeutics is developing immunotherapies for solid and hematologic cancers.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
Cell works	Consulting	ongoing	Not a conflict. Cellworks markets and is developing technologies for personalizing cancer treatment.
RiverVest	Consulting	ongoing	Not a conflict. RiverVest is a venture capital firm specializing in the life sciences.
BMS	Travel	ongoing	Direct conflict. Bristol-Myers Squibb markets hydroxyurea, which will be addressed by these guidelines.
Asterias Bio Therapeutics	Travel	ongoing	Not a conflict. Asterias Biotherapeutics markets and is developing cellular therapies for neurology and oncology..
Amphivena	Travel	ongoing	Not a conflict. Amphivena is developing cellular therapies for hematologic cancers.
Bluebird bio	Travel	ongoing	Indirect conflict. Bluebird Bio is developing a potentially disease-modifying gene therapy for SCD. The therapy is not yet to market and will not be specifically addressed in these guidelines; however, the company could be indirectly affected by recommendations that explicitly or implicitly suggest there is a need

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
			for curative therapies for SCD.



# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces,

markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

ASH education article Dec 2016

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

No

Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>

## Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

Don't know

No

Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

Don't know

No

Yes

If yes, please explain:

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

### Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

My university would support my work.

### Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

Ped and young adult sickle cell.

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain: I screen all of the patients for CNS injury. For children 2-16 with SS or Sbeta thal null, I order TCD screening. I request at least a baseline MRI for all patients with SCD. Based on the results of the TCD and MRIs, I might recommend transfusions or hydroxyurea. For patients with stroke, I often offer bone marrow transplant. I am also referring many patients for cognitive evaluations based on their imaging or clinical complaints.

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:

I screen for CNS complications. I might change interventions based on these guidelines.

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
WuGen	Dr. King’s husband is a co-founder of this company. It has no products now, but it will eventually try to produce “off the shelf” CART cells for cancer. They have shares with no real value at this time.	4/17/19	Not a conflict. This company does not have any products that could be affected by these guidelines.
Pfizer	Via email, Dr. King reports “In 2018, CMS reports me collecting ~\$18 from Pfizer. They brought lunch at work one day, but I didn’t actually eat it!”	4/17/19	Not a conflict. Dr. King disputes this claim.

## Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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### Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 3/17/17; Panepinto 3/23/17; Kunkle 1/22/18; Panepinto 1/24/18	Yes	Yes	<p>Dr. King reports that her husband receives ongoing direct transfers of value (travel support) from Bristol-Myers Squibb, which markets hydroxyurea. This direct conflict of interest will be managed by recusal on a recommendation by recommendation basis. A majority of the guideline panel does not have this same (or similar) conflict.</p> <p>Dr. King and her husband own stock in Magenta Therapeutics, which is developing gene and cell technologies and therapeutics, including for use in stem cell transplantation for SCD. Although these guidelines will not address stem cell transplantation, the company could be indirectly affected by recommendations that explicitly or implicitly suggest there is a need for curative therapies for SCD.</p> <p>Dr. King's husband receives direct payments from biotech companies that market or are developing gene or cell therapies, including Celgene (which owns Acetylon), Bioline, and Bluebird Bio. Like Magenta Technologies, these companies could be indirectly affected by these guidelines.</p> <p>These indirect conflicts will be managed by disclosure and panel composition.</p>
Webb 4/17/19; Panepinto 6/9/2019	Yes	Yes	<p>See new disclosure in Part D. above.</p> <p>On June 28, 2019 Dr. King confirmed all information in this form.</p>



Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>
BMS	Spouse receives ongoing direct transfers of value (travel support)	3/17/17	Bristol-Myers Squibb markets hydroxyurea. (ASH staff note: before determining recusals, research further if BMS also markets other products addressed by the guidelines, such as thrombolytics.)

Other Notes

Dr. King is a hematologist/oncologist who specializes in pediatric and adolescent SCD. In her clinical practice, she screens patients for CNS injury using TCD and MRI; recommends treatments including transfusion, hydroxyurea, and bone marrow transplant; and refers for cognitive evaluation. She has published an educational article on the guideline topic.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
Shire	Honoraria, meeting registration, meals	December 2016	Ended before appointment.

### My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
Shire	Quality of life for children prescribed rescue medication for seizures	PI for local UK site in Southampton	Dec 2015	Ended before appointment.

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made? Careful and balanced review of the pathophysiology and available treatment options for (1) CNS complications (2016) and (2) silent cerebral infarction (2012), both co-authored with Dr DeBaun and published after peer review in Blood; editorial with Dr DeBaun on TWITCH trial in Lancet (2016); review in Nature Clinical Practice Neurology (2007); review of treatment options with Dr DeBaun in Expert Reviews in Hematology (2004)

## Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No
- Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>
NIHR Research for Patient Benefit (UK) and Great Ormond Street Children’s Charity	Randomised trial of auto-adjusting CPAP in sickle cell disease	Chief Investigator	Dec 2017
Action Medical research (UK)	Randomised trial of Montelukast in sickle cell disease	Chief Investigator	Dec 2020

## Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don’t know
- No
- Yes

If yes, please explain:



5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

Don't know

No

Yes

If yes, please explain:

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

## Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

I would be fully supported by mentors and institutions

## Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

- No  
 Yes

If yes, what is your primary specialty or subspecialty?

Pediatric Neurology

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

- No  
 Yes

If yes, please explain:

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

- No  
 Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
Eisai	Receives ongoing direct transfers of value for (honoraria, meals, and meeting registration) for Eslicarbezepine trial. Eslicarbezepine is an anticonvulsant therapy used to treat epilepsy.	4/18/19	Not a conflict. Eisai does not have any products that could be affected by these guidelines.
Shire (now owned by Takeda)	Direct payment for Speaker Bureau role on PERFECT study of buccal Midazolam for emergency termination of status epilepticus.	4/18/19	Indirect conflict. Shire is investigating Aes-103 and ADAMTS13 for SCD. Although these guidelines did not make specific recommendations about these investigational drugs, the company could be indirectly affected by the guidelines because the recommendations could suggest a need for new or better therapies to treat SCD complications such as VOC. This disclosure was made after recommendations were formed.
Shire	Published two manuscripts from the previously disclosed study on "Quality of life for children prescribed rescue	4/18/19	Update to previous disclosure. See above.

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
	medication for seizures”		

## Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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### Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 3/3/17; Panepinto 3/5/17; Kunkle 1/23/18; Panepinto 1/24/18	No	No	
Webb 5/23/19 Panepinto 6/9/2019	No	No	See new disclosure in Part D. above. Other notes added below. On July 2, 2019, Dr. Kirkham confirmed all information in this form.

### Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

### Other Notes

Dr. Kirkham is a pediatric neurologist. Dr. Kirkham has published reviews and editorials about interventions for patients with CNS complications including silent cerebral infarction. She is the principal investigator for a clinical trial of montelukast (an anti-inflammatory medication used for asthma) in patients with SCD. The trial is funded by the U.K. charitable organization Action Medical Research. She was also the principal investigator of a clinical trial of auto-adjusting CPAP in patients with SCD that was funded by the U.K. NIHR Research for Patient Benefit and Great Ormond Street Children’s Charity, and she was an investigator for a study funded by Shire about quality of life in

products specific to SCD treatment, however they are investigating two new therapies for SCD. She has advised Eisai on the results of their randomized controlled trial of Eslicarbezepine, an anticonvulsant, in children with epilepsy. An abstract from this RCT has been accepted for the European Paediatric Neurology Society meeting in September 2019 (she was local PI for this trial, mentioned above, before the guideline committee was convened).

Dr. Kirkham also received research funding from Great Ormond Street Children's Charity to fund a research fellow undertaking MRI in SCD.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

**No**

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

**No**

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

**No**

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

**No**

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.



Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

**No**

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

**No**

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

**No**

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

**No**

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

**No**

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

**No**

Yes

If yes, what were those views and where were they made?

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

**No**

Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>

## Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

Don't know

**No**

Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

Don't know

**No**

Yes

If yes, please explain:

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

**No**

Yes

If yes, please explain:

### Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution? **Likely no reaction, but if any, I predict supportive.**

### Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

**No**

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

**Yes**

If yes, what is your primary specialty or subspecialty? **Neuroradiology**

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

**No**

Yes

If yes, please explain:

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

**No**

Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>



# Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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## Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 2/23/17; Panepinto 3/5/17; Kunkle 1/23/18; Panepinto 1/24/18	No	No	
Webb 4/16/19	No	No	On April 5, 2019, Dr. Kraut confirmed all information in this form.

## Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

## Other Notes

Dr. Kraut's clinical specialty is neuroradiology.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
Siemens	Honorarium, Travel	1/2017	Direct conflict. Siemens markets laboratory and medical imaging equipment. Although these guidelines will not offer recommendations for or against any specific device or equipment, the company could be affected by recommendations to do or not do screening and monitoring interventions using any such equipment, although perhaps trivially so because SCD is a rare disease. This paid activity ended shortly after Dr. McKinstry’s appointment to the guideline panel and before the panel agreed on clinical questions.
Guerbet, LLC	Honorarium, Travel	6/2015	Ended before appointment. See annotation under Part B, Question 1.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner's or Spouse's Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
Guerbet	Evaluate Contrast Agent	Site PI	Ongoing	Indirect conflict. Guerbet markets medical imaging products such as contrast dyes. The company could be indirectly affected by recommendations to do or not do imaging, although perhaps trivially affected because SCD is a rare disease.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:



## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain: I believe that silent cerebral infarcts are an important predictor of future risk for cerebral infarct (silent and overt). I believe that cerebral vascular disease in the setting of sickle cell disease is a major risk factor for infarction (overt and silent)

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

I wrote a review article with Mike DeBaun.

Debaun MR, Armstrong FD, **McKinstry RC**, Ware RE, Vichinsky E, Kirkham FJ. Silent cerebral infarcts: a review on a prevalent and progressive cause of neurological injury in sickle cell anemia. Blood. 2012 May 17;119(20):4587-96. Epub 2012 Feb 21. PubMed PMID: 22354000.

## Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No  
 Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>

## Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don't know  
 No  
 Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

- Don't know

No

Yes

If yes, please explain: I read brain MRIs from adults and children with sickle cell disease.

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain: If the number of MRIs increase/decreases the amount of revenue generated will fluctuate. SCD makes up a tiny fraction of the number of MRIs we perform each year.

## Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

I am a tenured full professor. No effect.

## Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

Neuroradiology

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain: I don't order MRIs but based on the MRI results, I occasionally recommend other testing. MRA, TCD, CT scan etc.

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
Siemens	Direct transfers of value (meals) in 2017.	3/20/19	Direct conflict as noted above.
Philips Electronics	Direct transfers of value (meals) in 2017.	3/20/19	<p>Direct conflict. Philips markets laboratory and medical imaging equipment. Although these guidelines will not offer recommendations for or against any specific device or equipment, the company could be affected by recommendations to do or not do screening and monitoring interventions using any such equipment, although perhaps trivially so because SCD is a rare disease.</p> <p>This disclosure was made after recommendations were formed.</p>

## Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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### Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 2/23/17; Panepinto 3/5/17; Kunkle 1/22/18; Panepinto 1/24/18	Yes	Yes	<p>Dr. McKinstry reports direct payment and travel support from Siemens, which markets laboratory and medical imaging equipment. Although these guidelines are not expected to offer recommendations for or against any specific device or equipment, the company could be affected by recommendations to do or not do screening and monitoring interventions using any such equipment, although perhaps trivially so because SCD is a rare disease. This paid activity ended shortly after Dr. McKinstry's appointment to the guideline panel and before the panel agreed on clinical questions; therefore, recusal will not be required. This conflict will be managed through disclosure and panel composition.</p> <p>Dr. McKinstry is involved in research funded by Guerbet, which markets medical imaging products such as contrast dyes. The company could be indirectly affected by recommendations to do or not do imaging, although perhaps trivially so. He does not have a leadership role in the research, and all funding goes to his institution. This indirect conflict will be managed through disclosure and panel composition. Recusal will not be required.</p>
Webb 4/5/19 Panepinto 6/9/2019	Yes	Yes	<p>See new disclosures in Part D. above.</p> <p>On June 29, 2019 Dr. McKinstry confirmed all information in this form.</p>

Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

Other Notes

Dr. McKinstry is a specialist in neuroradiology. In his clinical practice, reads MRIs and recommends follow-up testing such as MRA, TCD, and CT scan. He reports that patients with SCD make up a tiny fraction of the number of MRIs his institution performs. With the guideline panel chair (Dr. DeBaun), he has authored a review article on silent cerebral infarcts in patients with sickle cell anemia.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.



<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces,

markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

- NHLBI guidelines and another paper with NHLBI panel on gaps in SCD research.
- [RARE-Best practices](#)

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No
- Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>

### Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don't know
- No
- Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

- Don't know
- No
- Yes

If yes, please explain:

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

### Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

Very supportive.

### Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>
<a href="#">RARE-Best practices</a>	Pilot on SCD guidelines as a rare disease	Panelist

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain:

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:

My program will conduct systematic reviews to support this guideline commissioned by ASH.



## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>

# Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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## Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 3/1/17; Panepinto 3/17/17; Kunkle 1/23/18; Panepinto 1/24/18	No	No	
Webb 4/16/19	No	No	On April 6, 2019, Dr. Murad confirmed all information in this form.

## Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

## Other Notes

Dr. Murad is conducting systematic reviews to support these guidelines under a contract with ASH. He previously supported the development of guidelines on SCD published by the National Heart, Lung and Blood Institute, including the development of a paper on gaps in SCD research. He also served on a guideline panel on SCD for RARE-Bestpractices, a pilot project funded by the European Union to explore methods for developing guidelines on rare diseases.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces,

markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?



- No
- Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>

### Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don't know
- No
- Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

- Don't know
- No
- Yes

If yes, please explain:

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

### Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

N/A

### Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain:

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>

# Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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## Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 3/6/17; Panepinto 3/20/17; Kunkle 1/23/18	No	No	
Webb 4/16/19	No	No	On April 6, 2019, Mrs. Rivera confirmed all information in this form.

## Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

## Other Notes

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# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner’s or Spouse’s Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>



# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces,

markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain: I believe that guidelines such as these can be a potent way to influence health practices and improve the care of patients.

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No
- Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>
Palmetto Health Foundation	Evaluation of the predictive validity of developmental screening for identifying children who progress toward higher stroke risk	PI	ongoing

### Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don't know
- No
- Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

- Don't know

No

Yes

If yes, please explain:

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

### Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution? I believe I would receive strong support from my institution and colleagues, but you never know until it happens, do you?

### Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

Clinical Psychology / Clinical Neuropsychology

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain: I recommend behaviorally-based assessments and interventions, such as developmental assessments, neuropsychological assessments, cognitive remediation, environmental supports, etc.

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>

# Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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## Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 3/2/17; Panepinto 3/5/17; Kunkle 1/23/18; Panepinto 1/24/18	No	No	
Webb 4/16/19	No	No	On April 10, 2019, Dr. Schatz confirmed all information in this form.

## Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

## Other Notes

Dr. Schatz is a clinical psychologist with a clinical and research focus on cognitive development in children with SCD. In his practice, he recommends behaviorally based assessments and interventions, such as developmental assessments, neuropsychological assessments, cognitive remediation, or environmental supports. He is the principal investigator on research funded by the Palmetto Health Foundation about evaluation of predictive validity of developmental screening for identifying children who progress toward higher stroke risk.





# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
GBT	Episodic service on advisory committee	On-going	Indirect conflict. Global Blood Therapeutics is developing GBT 440, a potentially disease-modifying therapy for SCD. This drug is not yet to market and will not be specifically addressed in these guidelines; however, the company could be indirectly affected by recommendations that implicitly or explicitly identify a need for a disease-modifying therapy that might prevent SCD complications such as CNS complications.
Novartis Pharma	Episodic service on advisory committee	On-going	Indirect conflict. Novartis markets products for iron overload, a complication of transfusion. Although these guidelines will not make specific recommendations about management of iron overload, the company could be indirectly affected by recommendations to do or not do transfusion.
Pfizer	Chair of external data monitoring committee	On-going	Direct conflict. Pfizer manufactures streptokinase, a

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
	for new therapeutic product		thrombolytic used to treat acute stroke. These guidelines will address use of thrombolytics. Pfizer is also investigating efficacy of the phosphodiesterase 9 inhibitor PF-04447943 in combination with hydroxyurea to prevent vaso-occlusive crises. Recommendations about hydroxyurea might indirectly affect approval and marketing of this drug.
Apopharma	Episodic speakers bureau involvement	On-going	Indirect conflict. ApoPharma markets deferiprone, used for iron overload, a complication of transfusion. Although these guidelines will not make specific recommendations about management of iron overload, the company could be indirectly affected by recommendations to do or not do transfusion.
Napp Pharma	Funding for investigator-led trial	Lump sum (£3000)	Not a conflict. Napp does not market any products specific to SCD.
Bluebird Bio	Episodic service on advisory committee	On-going	Indirect conflict. Bluebird Bio is developing a gene therapy for SCD. Although these guidelines will not

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
			address this therapy, the company could be indirectly affected by recommendations that explicitly or implicitly suggest there is a need for curative therapies for SCD.

### My Partner's or Spouse's Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate “current” or “ongoing.”)

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
GBT	Phase 2 trial Phase 3 trial	PI PI	Feb 2017 In start-up	Indirect conflict. As noted above, Global Blood Therapeutics could be indirectly affected by these guidelines.
Pfizer	Phase 2 trial	PI	Start -up	Indirect conflict. As noted above, Pfizer could be directly and indirectly affected by these guidelines.
Celgene	Phase 3 trial	PI	On-going	Indirect conflict. In 2016, Celgene acquired Acetylon. Acetylon is in the preclinical phase of

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
				developing a potentially disease-modifying therapy for SCD. The therapy is not yet to market and will not be specifically addressed in these guidelines; however, the company could be indirectly affected by recommendations that implicitly or explicitly identify a need for a disease-modifying therapy that might prevent SCD complications such as CNS complications.
Apopharma	Phase 3 trial	PI	On-going	Indirect conflict. As noted above, ApoPharma could be indirectly affected by these guidelines.
Napp Pharma	Phase 2 trial	CI	On-going	Not a conflict. As noted above, Napp does not market any products specific to SCD.
Kyowa Kirin Limited	Phase 2 trial	CI	On-going	Not a conflict. Kyowa Kirin does not market and is not developing any products specific to SCD.

### Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces,

markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

## Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:



## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

Guidelines and original articles in peer-reviewed journals.

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

- No
- Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>
No funding	Outcomes of TCD screening in E London	Lead author	May 2016

## Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

- Don't know
- No
- Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

- Don't know
- No
- Yes

If yes, please explain:

All clinical activity is coded and billed to local or national commissioners. This is standard National Health Service arrangement in England

6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

Generate further referrals of affected patients

## Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

Very supportive

## Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>
UK Forum for Haemoglobin Disorders	Supports evidence-based recommendations	Vice Chair
UK National Clinical Reference Group for Specialised Commissioning in Haemoglobinopathies	Commissions specialized NHS services on the basis of evidence based recommendations	Committee member
British Society for Haematology	Supports and produces evidence-based guidelines	Committee member
Royal College of Pathologists	Supports evidence-based guidelines	Member

## Clinical Practice

9. Do you see patients clinically?

- No  
 Yes

If yes, what is your primary specialty or subspecialty?

Haematology and Paediatric Haematology

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

- No  
 Yes

If yes, please explain:

All interventions in sickle cell disease in children and adults

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

- No  
 Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
Bluebird Bio	Signed contract for research funding in September 2017, will continue for 15 months	1/29/18	Indirect conflict. As noted above (Part A, Question 4), Bluebird could be indirectly affected by these guidelines.
Terumo	Direct payment for speaker's bureau. He was paid to give a talk on local experience with automated exchange transfusion at the ASCAT meeting in London October 2017	1/29/18	Direct conflict. Terumo markets an apheresis system and protocols used for transfusion. The system is specifically indicated by FDA for treating children and adults with SCD. Although SCD is a rare disease, patients with SCD are frequently transfused. Recommendations for transfusion could enhance the company's ability to market its system to hospital and clinic settings where patients with SCD are treated.

## Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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### Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 2/24/17; Panepinto 3/12/17; Kunkle 1/23/18; Panepinto 1/24/18	Yes	Yes	<p>Dr. Telfer receives direct payments from Pfizer, and he is the principal investigator on research funded by Pfizer. The company manufactures streptokinase, a thrombolytic used to treat acute stroke. These guidelines will address use of thrombolytics. Recusal from recommendations about thrombolysis will be required. A majority of the guideline panel does not have the same or similar direct financial conflict.</p> <p>Pfizer is also investigating efficacy of the phosphodiesterase 9 inhibitor PF-04447943 in combination with hydroxyurea to prevent vaso-occlusive crises. Recommendations about hydroxyurea might indirectly affect approval and marketing of this drug. This indirect conflict will be managed through disclosure and panel composition.</p> <p>Dr. Telfer also receives direct payments from or is the principal investigator on research funded by other companies that could be indirectly affected by the guidelines. These include companies that are developing curative or disease-modifying therapies (i.e., Global Blood Therapeutics, Bluebird Bio, Celgene) and companies that market products used for iron overload, a complication of transfusion (i.e., Novartis, Apopharma). These indirect conflicts will be managed through disclosure and panel composition. Recusal will not be required.</p>
Webb 4/2/18; Kunkle 4/3/18	Yes	Yes	See new disclosures in Part D above. Dr. Telfer has received direct payment from Terumo, which markets an apheresis machine and protocols for transfusion. These guidelines will address the use

			<p>of apheresis (exchange transfusion). Recusal from relevant recommendations will be required.</p> <p>Dr. Telfer also has new research funding from Bluebird Bio. Funding goes to his institution. This indirect conflict will be managed by disclosure and by panel composition. Recusal will not be required.</p>
Webb 5/10/19	Yes	Yes	On May 10, 2019, Dr. Telfer confirmed all information in this form.

### Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>
Pfizer	Direct payments or other transfers of value for chairing an external data monitoring committee	2/24/17	Pfizer manufactures streptokinase, a thrombolytic used to treat acute stroke.
Terumo	Direct payment for talks given as part of speaker's bureau.	2/29/18	Terumo markets an apheresis system and protocols used for transfusion.

### Other Notes

Dr. Telfer is a hematologist who specializes in pediatric SCD. In his clinical practice, he sees and treats both children and adults with SCD. He has authored related guidelines or served on guideline committees for the U.K. Forum for Haemoglobin Disorders, the U.K. National Clinical Reference Group for Specialised Commissioning in Haemoglobinopathies, the British Society for Haematology, and the Royal College of Pathologists.



# ASH Guideline Panel Declaration of Interests Form

## Part A. Direct Financial Interests in or Relationships With Companies

### Employment

1. Are you currently or in the past 24 months have you been an employee of any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each employment relationship.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Equity

2. Do you currently or in the past 24 months have you had equity in any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions? Equity includes stock, stock options, and other ownership interests but excludes diversified mutual fund shares.

No

Yes, as described below:

Add rows as needed for each equity interest.



<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Patents, Royalties, and Other Intellectual Property

3. Do you currently or in the past 24 months have you owned patents for or received royalties from any intellectual property or product used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Add rows as needed for each patent or royalty interest.

<i>Company</i>	<i>Description</i>	<i>Date Divested</i>	<i>For ASH Internal Use</i>

### Personal Income or Other Direct Transfers of Value

4. Do you currently or in the past 24 months have you received any personal income or other direct transfers of value (e.g., honoraria, gifts, travel support, meeting registration, meals) from any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company.

Column 2 Describe the activity for which you received the income or other transfer of value, e.g., research, consultancy, speakers bureau involvement, service on an advisory committee or board, expert testimony.

Column 3 Indicate when the activity ended, if applicable. (If the activity has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each activity.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### My Partner's or Spouse's Interests

5. Currently or in the past 24 months has *your partner or spouse* had any of the interests or relationships described in questions 1-4?

No

Yes, as described below:

Add rows as needed for each interest.

<i>Company</i>	<i>Description</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

# Part B. Indirect Financial Interests in or Relationships With Companies

## Industry-Funded Institutional Research

1. Through your institution, do you currently or in the past 24 months have you been involved in research funded or supported (e.g., in kind support, such as provision of a study drug) by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the company funding or supporting the research.

Column 2 Briefly describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each research project.

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
Novartis	Iron chelation trial in thal	PI	Jan. 2017	Ended before appointment.
Pfizer	Rivipansel	Adjudication Committee	ongoing	Indirect conflict. Rivipansel is being developed for treatment of vaso-occlusive crisis. In addition to this drug, Pfizer is investigating efficacy of the phosphodiesterase 9 inhibitor PF-04447943 in combination with hydroxyurea to prevent vaso-occlusive crises. Recommendations

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
				about hydroxyurea might indirectly affect approval and marketing of this drug. Pfizer also manufactures streptokinase, a thrombolytic used to treat acute stroke. These guidelines will address use of thrombolytics.
ApoPharma	Iron chelation in sickle cell	PI	ongoing	Indirect conflict. ApoPharma markets deferiprone, used for iron overload, a complication of transfusion. Although these guidelines will not make specific recommendations about management of iron overload, the company could be indirectly affected by recommendations to do or not do transfusion.
iNKT Therapeutics	Phase I sickle cell	PI	Ended Oct. 2016	Ended before appointment.
Emmaus	Glutamine	PI	2016	Ended before appointment.
Gamida Cell	Stem cell transplant	Adjudication Committee	ongoing	Indirect conflict. Gamida Cell is developing technologies to enable cellular and immune therapies including bone marrow transplantation for SCD. Although these guidelines will not address this therapy,

<i>Company</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>	<i>For ASH Internal Use</i>
				the company could be indirectly affected by recommendations that explicitly or implicitly suggest there is a need for curative therapies for SCD.
Bluebird bio	Gene therapy	Co-PI	ongoing	Indirect conflict. Bluebird Bio is developing a gene therapy for SCD. Although these guidelines will not address this therapy, the company could be indirectly affected by recommendations that explicitly or implicitly suggest there is a need for curative therapies for SCD.
Mast	MST-188 trial	PI	2016	Ended before appointment.

### Paid and Volunteer Activities for Organizations Supported by Industry

2. Do you currently or in the past 24 months have you been involved in any volunteer or paid work for an organization that is wholly or partially funded by any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes, as described below:

Column 1 Name the organization. If known to you, describe any industry funding or support.

Column 2 Briefly describe your activity and role, e.g., employment, service on board of directors, other volunteer services.

Column 3 Indicate if your activity was paid or volunteered.

Column 4 Indicate when your involvement with the organization ended. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each organization.

<i>Organization</i>	<i>Description and role</i>	<i>Paid or Unpaid?</i>	<i>End Date</i>	<i>For ASH Internal Use</i>

### Other

3. Do you have other indirect interests in or relationships with any for-profit company that develops, produces, markets, or distributes drugs, devices, services, or therapies used to diagnose, treat, monitor, manage, or alleviate health conditions?

No

Yes

If yes, please explain:

## Part C. Relevant Other Interests That Are Not Mainly Financial

You have been invited by ASH to participate in the development of clinical practice guidelines on the following topic(s):

Sickle Cell Disease-Related Cerebrovascular Disease

The questions that follow are designed to elicit information about personal beliefs, intellectual positions or opinions, institutional relationships, and other interests that are not mainly financial and that may be relevant to guidelines on the above topic(s).

### Personal Beliefs

1. Do you have strongly held beliefs related to the topic of these guidelines?

No

Yes

If yes, please explain:

### Previously Published Opinions

2. Have you ever authored, coauthored, or publicly provided an opinion related to the topic of these guidelines, e.g., a clinical practice guideline, textbook, review article, meeting poster or presentation, grand rounds talk, letter to the editor?

No

Yes

If yes, what were those views and where were they made?

Up-to-Date author on sickle cell disease management. Uptodate.com

### Non-Industry Supported Research

3. Currently or in the past 24 months, have you been involved in a leadership role in any research project not already reported under Part B, Question 1, relevant to the topic of these guidelines, e.g., a research project funded by a nonprofit or governmental organization?

No

Yes, as described below:

Column 1 Name the entity funding the research.

Column 2 Describe the research project.

Column 3 Describe your role: (a) national or overall principal investigator, (b) member of a steering committee of a study that does not have a principal investigator, (c) site or local investigator. If other than these options, please describe.

Column 4 Indicate when your involvement ended, if applicable. (If your involvement has not yet ended, indicate "current" or "ongoing.")

Add rows as needed for each research project.

<i>Funder</i>	<i>Description of Research</i>	<i>My Role</i>	<i>End Date</i>
HRSA	Pacific Sickle Cell Regional Collaborative	Co-PI	ongoing
NHLBI	Sickle Cell Disease Implementation Comm	Co-PI	Ongoing

## Institutional Relationships

4. Could your salary be affected by recommendations on this topic?

Don't know

No

Yes

If yes, please explain:

5. Do you generate revenues for your institution or employer by clinical activity, teaching, speaking, consulting, testifying, writing, or otherwise sharing your knowledge or opinions about this guideline topic?

Don't know

No

Yes

If yes, please explain:



6. Could your institution benefit or be harmed by recommendations of guidelines on this topic?

Don't know

No

Yes

If yes, please explain:

### Career Advancement

7. How would you characterize the support you would receive from your primary mentor, institution, or other entities if your work on this panel or authorship of these guidelines generated a strong reaction from peers outside your institution?

No effect.

### Involvement in Organizations With Relevant Policy Positions

8. Do you work for or are you a member of an organization with a stated position related to the topic of these guidelines, e.g., position statement, editorial, blog, amicus brief, or legislature or legal testimony?

No

Yes, as described below:

Column 1 Name the organization.

Column 2 Describe or reference any policy position of the organization that is related to the topic of these guidelines.

Column 3 Describe your role at the organization, including your involvement in deciding, promoting, or implementing relevant positions.

Add rows as needed for each organization.

<i>Organization</i>	<i>Relevant Policy Position</i>	<i>Your Role</i>

## Clinical Practice

9. Do you see patients clinically?

No

Yes

If yes, what is your primary specialty or subspecialty?

Hemoglobinopathies, pediatric hematology oncology

If yes, do you prescribe or otherwise recommend clinical interventions (e.g., screening or diagnostic tests, evaluations, treatments, procedures) that may be addressed by these guidelines?

No

Yes

If yes, please explain: I recommend Transcranial Doppler screening for children with sickle cell anemia and hydroxyurea therapy based on evidence-based guidelines from NIH.

## Expected Interests

10. Do you expect new financial or nonfinancial interests relevant to the topic of these guidelines not already declared in this form?

No

Yes

If yes, please describe:

## Part D. New Declarations (ASH Internal Use)

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
Bluebird Bio	Clarification: The research on gene therapy funded by Bluebird Bio that is reported above under Part B, Question 1, relates to thalassemia, not SCD.	1/23/18	The fact that the research is not focused on SCD makes this a more indirect conflict.
Catalyst BioScience	Direct payment for consulting (evaluate pre-clinical and/or clinical data for products in SCD). Paid 9/28/16.	1/23/18	Not a conflict. This paid activity ended before Dr. Vichinsky's appointment to the guideline panel.
CSL Behring	Direct payment for consulting on possible new therapies for SCD. Paid 2/2016.	1/23/18	Not a conflict. This paid activity ended before Dr. Vichinsky's appointment to the guideline panel.
Ironwood Pharmaceuticals	Direct payment for consulting on potential use of IW-1701 for SCD. Paid 2017.	1/23/18	Indirect conflict. Ironwood Pharmaceuticals is investigating a soluble guanylate cyclase stimulator (IW-1701) for SCD. Although this product is not yet to market and will not be addressed by these guidelines, the company could be indirectly affected by recommendations that explicitly or implicitly suggest a need for a new disease-modifying therapy to address the

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
			causes of acute and chronic complications of the disease.
ZoneOne Pharma	Direct payment for consulting on liposomal DFO for iron overload. Last activity 1/2017.	1/23/18	Indirect conflict. ZoneOne Pharma is developing a liposomal formulation of the FDA approved iron chelator deferoxamine, used for iron overload, a complication of transfusion. Although these guidelines will not make specific recommendations about management of iron overload, the company could be indirectly affected by recommendations to do or not do transfusion.
Novartis	Direct transfers of value (meals and travel support) in 2017. Relationship ongoing	3/20/19	Indirect conflict. Novartis markets products for iron overload, a complication of transfusion. Although these guidelines will not make specific recommendations about management of iron overload, the company could be indirectly affected by recommendations to do or not do transfusion. This disclosure was made after recommendations were formed.
Novartis	Direct payment for speaking engagement	3/20/19	Indirect conflict. See above.

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
	in 2017. Relationship ongoing.		
Novartis	A Phase 2, Multicenter, Open-Label Study to Assess Appropriate Dosing and to Evaluate Safety of Crizanlizumab, with or without Hydroxyurea/Hydroxycarbamide, in Sequential, Descending Age Groups of Pediatric Sickle Cell Disease Patients with Vaso-Occlusive Crisis. Ends 2022.	3/20/19	Indirect conflict. See above.
Pfizer	Consulting since 2014. Relationship ongoing.	3/20/19	Indirect conflict. See above. Funds go to his institution and not to him directly.
ApoPharma	Direct transfers of value (meals and travel support) in 2017.	3/20/19	Indirect conflict. See above.
Global Blood Therapeutics	Direct payment for steering committee role.	5/20/19	Indirect conflict. Global Blood Therapeutics is developing GBT 440, a potentially disease-modifying therapy for SCD. This drug is not yet to market and will not be specifically addressed in these guidelines; however, the company could be indirectly affected by recommendations that implicitly or explicitly identify a need for a disease-modifying therapy that might prevent SCD complications such as CNS

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
			recommendations were formed.
ApoPharma	Direct transfers of value (meals and travel support) in 2017.	3/20/19	Indirect conflict. See above.
Global Blood Therapeutics	Direct payment for steering committee role.	5/20/19	Indirect conflict. Global Blood Therapeutics is developing GBT 440, a potentially disease-modifying therapy for SCD. This drug is not yet to market and will not be specifically addressed in these guidelines; however, the company could be indirectly affected by recommendations that implicitly or explicitly identify a need for a disease-modifying therapy that might prevent SCD complications such as CNS complications. This disclosure was made after recommendations were formed.
Global Blood Therapeutics	Direct transfers of value (meals and travel support).	5/20/19	Indirect conflict. See above.
Bluebird bio	Direct payment for consultant role.	5/20/19	Indirect conflict. See above.
Agios	Direct payment for advisory board role.	5/20/19	Indirect conflict. Ironwood Pharmaceuticals is investigating a soluble guanylate cyclase stimulator (IW-1701) for SCD. Although this product is not yet to market and will not be

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Internal Notes</i>
			addressed by these guidelines, the company could be indirectly affected by recommendations that explicitly or implicitly suggest a need for a new disease-modifying therapy such as CNS complications. This disclosure was made after recommendations were formed.
Agios	Co-investigator for a phase II single arm, open label study of red blood cell pyruvate kinase (PKR) activator, AG-348, in nontransfusiondependent alpha and beta thalassemia	5/20/19	Indirect conflict. See above.
Sangamo	Sub-investigator for a phase 1/2, Open label, Single-arm Study to Assess the Safety, Tolerability, and Efficacy of ST-400 Autologous Hematopoietic Stem Cell Transplant for Treatment of Transfusion-dependent $\beta$ -thalassemia (TDT). Ended 3/12/18.		Indirect conflict. Sangamo is developing BIVV-003, a gene-edited therapy for SCD. Although these guidelines will not address this therapy, the company could be indirectly affected by recommendations that explicitly or implicitly suggest there is a need for curative therapies for SCD. This disclosure was made after recommendations were formed.

## Part E. Summary (ASH Internal Use)

Name of guideline panel(s)	ASH Guideline Panel on Sickle Cell Disease-Related Cerebrovascular Disease
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### Summary of ASH Judgments About Financial Conflicts

<i>Reviewer name and date</i>	<i>Direct Financial Conflicts?</i>	<i>Indirect Financial Conflicts?</i>	<i>Management Notes</i>
Webb 3/2/17; Panepinto 3/12/2017; Kunkle 1/23/18; Panepinto 1/24/18	No	Yes	<p>Dr. Vichinsky is involved in research funded by Pfizer. Pfizer could be directly affected by these guidelines because the company manufactures streptokinase, a thrombolytic used to treat acute stroke. Because SCD is a rare disease, the impact on the company could be trivial. The company is also developing therapies to prevent and treat vaso-occlusive crisis. Dr. Vichinsky does not have a leadership role in this research, and the funding goes to his institution. The research is related to rivipansel, not streptokinase.</p> <p>Dr. Vichinsky is involved in research funded by other companies that could be indirectly affected by these guidelines, including ApoPharma (which markets products for iron overload), Gamida Cell (which is developing technologies to enable cellular and immune therapies including bone marrow transplantation for SCD), and Bluebird Bio (which is developing a gene therapy for SCD). He is the principal investigator for the research project funded by ApoPharma. Funding for all of these research projects goes to his institution.</p> <p>All of the above indirect conflicts will be managed through disclosure and panel composition. Recusal will not be required.</p>
Kunkle 1/24/18	No	Yes	<p>New disclosures. See Part D, above. Dr. Vichinsky reports direct payments from Ironwood Pharmaceuticals and from ZoneOne Pharma. Ironwood is developing a disease-modifying therapy for SCD, and ZoneOne is developing a new therapy for iron overload, a complication of transfusion. Neither product is yet to market, and neither product will be specifically addressed by</p>



			<p>these guidelines. Nevertheless, the companies could be indirectly affected by recommendations that explicitly or implicitly suggest a need for the therapies.</p> <p>These indirect conflicts will be managed through disclosure and panel composition. Recusal will not be required.</p>
<p>Webb 5/24/19 Panepinto 6/9/2019</p>			<p>See new disclosures in Part D. above.</p> <p>Other notes added below.</p> <p>On August 28, 2019, Dr. Vichinsky confirmed all information in this form.</p>

Summary of Direct Financial Conflicts

<i>Company</i>	<i>Description</i>	<i>Disclosure Date</i>	<i>ASH Notes</i>

Other Notes

Dr. Vichinsky specializes in hemoglobinopathies and pediatric hematology and oncology. In his clinical practice, he recommends TCD screening and hydroxyurea therapy. In addition to the industry-funded research described above, he is the co-principal investigator on research about SCD funded by the Health Research Services Administration and the National Heart, Lung and Blood Institute (NHLBI). He has authored review articles on SCD management published by UpToDate. Dr. Vichinsky has a new NHLBI sponsored research study on hydroxyurea and cerebrovascular complications in SCD and he is also a new co-principal investigator on a REDS-IV-P recipient and donor study funded by the NHLBI. Dr. Vichinsky is a new co-PI on a sickle cell treatment demonstration program funded by the Center for Inherited Blood Disorders.