Supplementary material

HELP SCORE FINAL

Consent

Completing this survey helps validate this HG assessment tool so it can be used by health professionals to improve care of HG moms. Remember: **We are scoring the impact of nausea/vomiting on a specific day not the severity of HG during all or the worst of your pregnancy.** Trending the score reflects symptom changes and treatment effectiveness.

Important:

- *Estimated completion time is ~10-15 minutes.*
- Your score will show near the end.
- You will be emailed your results.
- Most questions are required.
- You can repeat this survey as your symptoms change.
- You can save your answers and finish later.

You will be asked series of easy questions to standardize the research, then about 1) your pregnancy, 2) symptoms, and 3) sleep and treatments. **Completing all required questions is necessary for research publication and will make this tool more helpful to HG mothers!**

NOTE: All information submitted will be kept strictly confidential and only used by researchers at the HER Foundation, UCLA and USC.

1. Do you consent to our use of your data *anonymously* for research? *

Your email will ONLY be used for validation and research-related communication.

I consent [contact("email")] (your email address)

2. Have you already submitted research data such as your race and education level for a different day of this pregnancy? *

This info is required to be part of our research. If you are unsure, check no.

- Yes
- No

3. Would you help us also validate a Quality of Life study by answering 7 very quick questions so we can see how HG impacts you?

- Yes
- No

Demographics for Research Requirements

4. What is your race?

You can skip this if you answered it previously.

- Black/African-American
- White/Caucasian
- Hispanic/Latino
- Native American
- Asian
- Mixed
- Other:

5. What is your highest level of completed education?

- ○ High School
- ○ Bachelor Degree
- ○ Graduate Degree
- ○ Professional/Technical Certificate
- ○ Other - Write In

6. What is your age today? *

7. What type of medical insurance/payment do you use?

- ☐ Government/State Program
- ☐ Private Insurance
- ☐ Self-Pay
- ☐ Other:

8. What is your work status today? *

- ○ Not employed outside the home
- ○ Employed/Student full-time
- ○ Employed/Student part-time (< 21 hours)
- ○ On disability/leave from work/school due to HG
- ○ Left the workforce due to HG
- ○ Other:

9. What is your living situation today? *

- ☐ Married
- ☐ Living with partner
- ☐ Not living with partner
- ☐ Living with family due to HG
- ☐ Situation changed due to HG
- ☐ Other:

10. What other CHRONIC health conditions did you have BEFORE your first pregnancy with HG?

- ☐ Headaches/Migraines
- ☐ Diabetes
- ☐ Chronic pain/fibromyalgia
- ☐ GI/Stomach problems
- ☐ Chronic anxiety/depression
- ☐ Other:

11. What if any health issues have you experienced MULTIPLE times during THIS PREGNANCY other than nausea/vomiting?

- ☐ Reflux
- ☐ Headaches
- ☐ Urinary infection
- ☐ Depression/Anxiety
- ☐ Constipation
- ☐ Other:

12. Please list the number of:

- ☐ Miscarriages/stillbirths
- ☐ Full term deliveries
- ☐ Terminations NOT due to HG
- ☐ Terminations due to HG
- ☐ Number of pregnancies with HG

Quality of Life Survey (Brief)

13. How much impact has nausea/vomiting had on:

	Major Impact	Minor Impact	No Impact	Not Applicable
Taking care of household chores?	○	○	○	○
Relationship with partner	○	○	○	○
Ability to care for other children	○	○	○	○
Work capacity (Ability to do normal job)	○	○	○	○

14. Have you:

	Yes	No	Unsure
Taken sick leave	○	○	○
Considered terminating due to HG	○	○	○
Considered not getting pregnant again	○	○	○

Your History

15. What is your height? (inches, cm, m) *
Note: 5 feet = 60 inches
PLEASE ENTER YOUR NUMBERS CAREFULLY

- ○ Inches:
- ○ Other (e.g. 5 ft 3 in):
- ○ Centimeters:
- ○ Meters:

16. **What was your weight BEFORE you became pregnant?** *
Please check your answers.

- pounds
- kg
- stone

17. **Did you have HG in a previous pregnancy?** *

- Yes
- No
- Maybe, Unsure
- This is my first pregnancy

18. **Are you currently pregnant?** *

- Yes
- Maybe
- No, this is based on a previous pregnancy
- Yes, but my answers are not based on my symptoms today

This tool is intended for use during pregnancy. Answer the questions that follow as you would have if you were still pregnant. Select a single point in your pregnancy such as the worst week, and answer as if you are at that point currently. So when it asks for weight loss, answer with your weight loss at that time in your pregnancy. When it asks for how many weeks pregnant you are, indicate the number of weeks for the time you are reporting. So, if you are looking to determine the severity of your previous pregnancy at 9 weeks, answer 9 weeks. Answer the remaining questions as if you were still at that point in time.

19. **How many weeks pregnant are you?** *
(in the pregnancy you are reporting on)

weeks

20. **Do you have hyperemesis gravidarum (HG)?**
HG is nausea and vomiting during pregnancy that

- causes debility & weight loss typically over 5%
- requires medical care: IV fluids and/or prescription medications, etc.

*

- Yes
- No
- Unsure - Optional comments:

21. **Your LOWEST WEIGHT since you became pregnant?** *

If you lost weight for a problem other than nausea/vomiting, state the diagnosis in comments.

- pounds
- kg
- stone
- No weight loss

Comments

22. Select any you have experienced AT ANY TIME during *THIS* pregnancy? *

Optionally indicate the duration and which weeks during your pregnancy. (example: 3 days, weeks 6-9)

- ☐ Outpatient/Clinic for IV's - Total number of visits:
- ☐ Inpatient hospitalization - Total number of days:
- ☐ ER visits - Total number of visits:
- ☐ Reason for hospitalization/ER if not HG:
- ☐ Comments:
- ☐ None of these

23. Have you had any of following treatments during *this* pregnancy? (duration is optional but helpful) *

- ☐ Home IV - Total # of weeks:
- ☐ Scheduled Clinic/ER IVs - Total # of visits:
- ☐ IV nutrition, PICC line, TPN - Total # of weeks:
- ☐ Gastric feeding tube (NG, NJ, G-tube) - Total # of weeks:
- ☐ Comments:
- ☐ None of these

24. Have you received IV fluids and/or nutritional treatments (TPN/NJ/G or PEG-tube) DURING THE LAST 7 DAYS? *

- ○ Yes
- ○ No

Severity Assessment Over Last 24 HOURS

Page description:
Answer questions based on the last 24 hours.

Answer these next 12 brief questions about your experience over the LAST 24 HOURS. THIS IS THE SEVERITY ASSESSMENT. After these, there are some additional questions about treatment and sleep, and your rating of the survey to help us validate your score! Thanks!

25. How much weight have you LOST THIS WEEK due to nausea and vomiting in your pregnancy? *

- None
- A little bit. (<.5 kg or 1 lb)
- A moderate amount. (0.5-1.5 kg, 2-3 lbs)
- A LOT! (1.5+ kg, 4+ pounds)

Comments

26. **Average nausea level over the last 24 hours:** *

- No Nausea
- 1 to 2 Minimal
- 3 to 4
- 5 to 6 Moderate
- 7 to 8
- 9 to 10 Worst

27. **Number of HOURS you have felt nauseated or sick to your stomach during the last 24 hours:** *

- None
- 1 hour or less
- 2 to 3 hours
- 4 to 6 hours
- 6-12 hours
- 12-24 hours

28. **Number of vomiting episodes during the last 24 hours:** *

- None
- 1 to 2 times
- 3 to 4 times
- 5 to 6 times
- 6 to 8 times
- 9 to 12 times
- 13+ times

29. **Number of times have you had retching or dry heaves without bringing anything up during the last 24 hours:** *

- None
- 1 to 2 times
- 3 to 4 times
- 5 to 6 times
- 6 to 8 times
- 9 to 12 times
- 13+ times

30. **You have been urinating ____ during the last 24 hours.** *

- Same, normal color
- Slightly less often, normal color
- More often, got IV fluids, light or dark color
- Once every 8 hours or slightly dark yellow
- Less than every 8 hours or darker/concentrated
- Rarely, very little, dark color, blood, or foul smell

31. **Average nausea/vomiting severity 1 hour after medication(s) or food during the last 24 hours:** *

If NO medications, indicate your average nausea/vomiting severity 1 hour after eating/drinking.

- None
- 1 to 2 MILD
- 3 to 4
- 5 to 6 MODERATE
- 7 to 8
- 9 to 10 SEVERE

32. **Number of hours you have been UNABLE TO WORK adequately at your job and/or at home over the last 24 hours DUE TO nausea and vomiting:** *

- 0 (hours are unchanged)
- 1-2 (hours slightly less)
- 3-4 (can work part-time)
- 5-7 (barely able to work)
- 8-10 (cannot care for family)
- 11+ (cannot care for myself)

33. **You have been coping with the nausea, vomiting and retching during the last 24 hours:** *

- Normally or effectively; no nausea/vomiting
- Fatigued but ok mood
- Slightly less than normal
- It's tolerable but difficult
- Struggling (e.g. moody, emotional)
- Poorly (e.g. depressed, irritable)

34. **Total amount you have been able to eat/drink AND keep it down for at least an hour over the last 24 hours:** *

This may not describe you exactly, just select the best one. A medium water bottle or large cup is usually 2 cups (16 ounces or 500 mL).

- Normally: 3 meals, snacks, 8+ cups fluid
- About 3 meals and 6+ cups fluid
- About 2 meals and 2-4 cups fluid
- About 1 meal and 1-2 cups fluid
- I can either drink fluids but can't eat, OR eat but not drink
- Very little, 0-1 meal and minimal fluids; AND/OR getting frequent IV/NG/NJ
- Nothing goes or stays down; AND/OR require daily NG/NJ/TPN

35. **Your anti-nausea/vomiting meds have stayed down/been tolerated over the last 24 hours:** *

- I'm not taking prescription medications
- Always
- Nearly always
- Sometimes
- Rarely
- Never/ **I get IV** or **SQ*** Meds
  *Subcutaneous pump or patch

36. **Your nausea/vomiting symptoms over the last 24 hours compared to last week:** *

- No Symptoms, Feeling Great
- A Little Better
- About The Same
- A Little Worse
- Much Worse
- SO Much Worse!

Time spent on page **Action: Hidden Value**
Value: Populates with the **length of time** since the survey taker started the current page

Treatments

37. **Number of prescribed (Rx) treatments are you receiving TODAY for nausea and vomiting?** *

Treatment examples: IV fluids, meds, tube feedings, PICC line.
Exclude meds for constipation, diabetes, etc.
(1 medication = 1 treatment regardless of the number of doses)
Example: Zofran + IV fluids + Reglan = 3

- None
- 1
- 2
- 3
- 4
- 5+

Comments

Scores

Respondent email address **Action: Hidden Value**
Value: [question("value"), id="61"]

PUQE 24 Score
Quiz Type: Tally

HELP Score Result #1

Quiz Type: Tally

HELP Score #2
(You will receive 2 scores. Please state which score is most accurate in the final question.)
Quiz Type: Tally

(untitled)

38. Have you been able to take and keep down your prenatal vitamins every day for the last 2 weeks? *

- Yes
- No
- Some days
- I don't take prenatals (but NOT because of nausea/vomiting)

39. **How would *you* rate the overall severity of nausea/vomiting symptoms and their impact on you TODAY:** *

Score how you are feeling even if you are doing well because of medications.

- NORMAL - no symptoms
- MILD - you can function still but feeling fairly miserable
- MODERATE - you are struggling to function and very miserable
- SEVERE - you are unable to function and constantly very sick

Comments

40. **How often did you receive the following treatments over the last 24 hours? ***

Zofran/ondansetron **4 mg**

1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None

Zofran/ondansetron **8 mg**

1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None

Reglan/metoclopramide

1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None

Kytril/granisetron/Sancuso

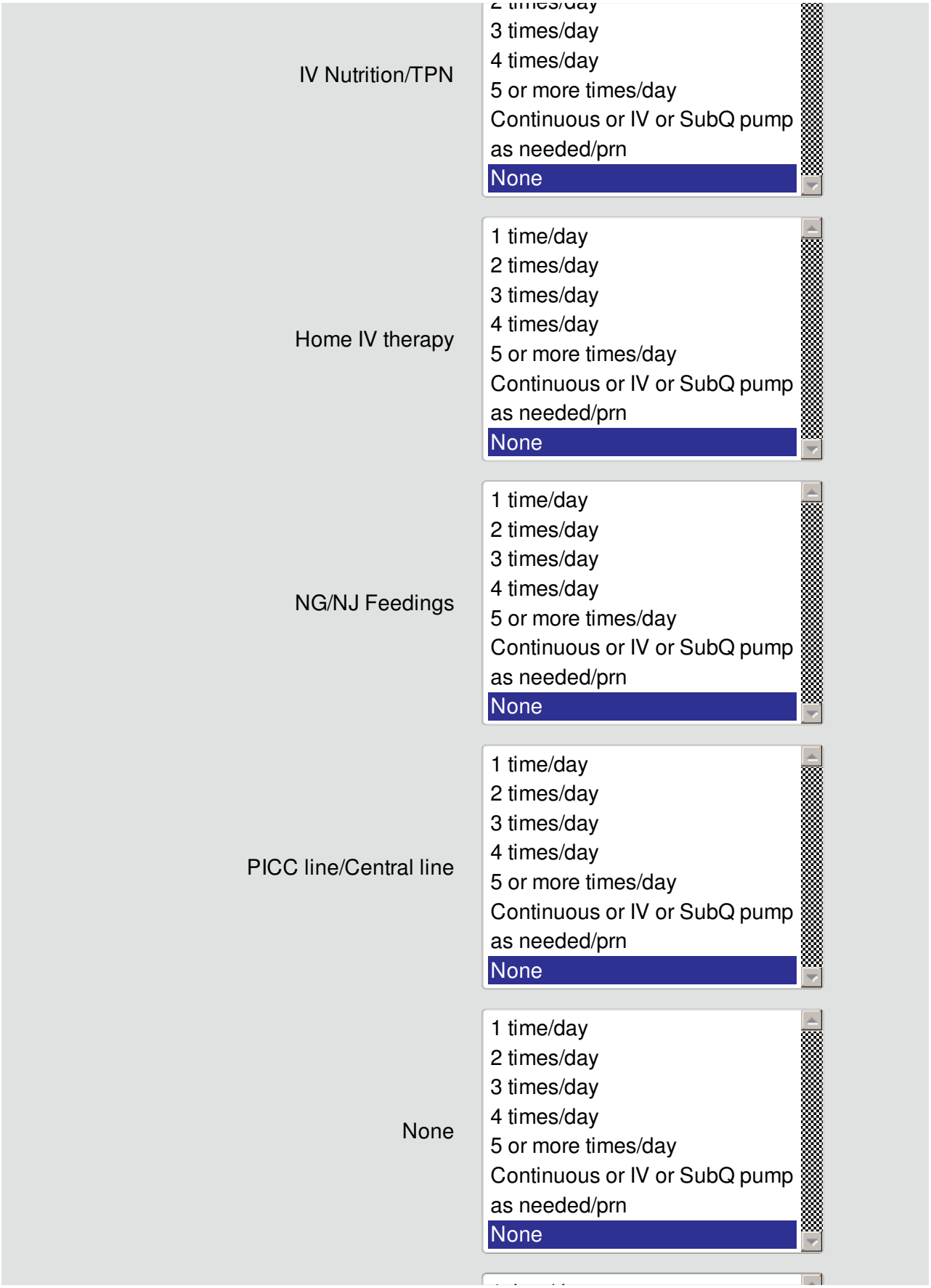
1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None

Diclectin/Diclegis

1 time/day
2 times/day
3 times/day
4 times/day

	5 or more times/day Continuous or IV or SubQ pump as needed/prn None
Unisom, Benadryl, Cyclizine, Meclizine	1 time/day 2 times/day 3 times/day 4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
Phenergan/promethazine	1 time/day 2 times/day 3 times/day 4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
Compazine/prochlorperazine, Stemetil	1 time/day 2 times/day 3 times/day 4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
Steroids/methylprednisone	1 time/day 2 times/day 3 times/day 4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
	1 time/day 2 times/day 3 times/day

Acid Reducer: Zantac (ranitidine)/Pepcid	4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
Acid blocker: Protonix/Prevacid/Prilosec	1 time/day 2 times/day 3 times/day 4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
Marijuana or Marinol	1 time/day 2 times/day 3 times/day 4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
Gabapentin/neurontin	1 time/day 2 times/day 3 times/day 4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
IV Fluids	1 time/day 2 times/day 3 times/day 4 times/day 5 or more times/day Continuous or IV or SubQ pump as needed/prn None
	1 time/day 2 times/day


3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None
IV Nutrition/TPN
1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None
Home IV therapy
1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None
NG/NJ Feedings
1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None
PICC line/Central line
1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None
None

OTHER: (list in comments)

1 time/day
2 times/day
3 times/day
4 times/day
5 or more times/day
Continuous or IV or SubQ pump
as needed/prn
None

Comments

Impact

HELP Score

Quiz Type: Tally

41. Your overall level of misery and debility DUE TO nausea/vomiting **TODAY**: *

1 = best possible for pregnancy & 10 = worst imaginable

Best Worst

Comments

42. Your overall level of misery and debility DUE TO nausea/vomiting **in your first trimester**: *

1 = best possible for pregnancy & 10 = worst imaginable

Best Worst

Comments

43. Your overall level of misery and debility DUE TO nausea/vomiting **in your second trimester:** (OPTIONAL)

1 = best possible for pregnancy & 10 = worst imaginable

Best Worst

Comments

44. Your overall level of misery and debility DUE TO nausea/vomiting **in your third trimester:** (OPTIONAL)

1 = best possible for pregnancy & 10 = worst imaginable

Best Worst

Comments

Additional Info

Page description:
Questions with an * are required.

45. You're almost done... How would you describe your sleep over the past week? *

- ☐ Normal or more: 6-9+ hours
- ☐ Broken: A few hours at a time + naps
- ☐ I require medication to sleep
- ☐ Poor sleep worsens my nausea/vomiting
- ☐ Total hours of sleep per day (average)
- ☐ Total hours per day on bedrest (average)
- ☐ Interrupted by nausea/vomiting/retching
- ☐ Interrupted by medical care (e.g. meds)
- ☐ Other comments:

46. **Vitamins or supplements you have received in the past 24 hours: ***

- ☐ None
- ☐ Prenatal multivitamin
- ☐ Vitamin B6/pyridoxine
- ☐ Folic Acid
- ☐ Thiamine/B1
- ☐ Vitamin B12
- ☐ Vitamin D
- ☐ IV multivitamin
- ☐ Children's multiple
- ☐ Iron
- ☐ Calcium
- ☐ Magnesium
- ☐ Vitamin C
- ☐ Fatty Acids/Fish Oils
- ☐ Other vitamins or specifics on dose/amount

47. Would you like to review your answers? *

- Yes
- No

Treatments & Score

Action: Review

Your answers:

Rating

Check the options that apply. *

This tool is for daily or weekly tracking of symptoms. It is not used to indicate your severity overall during pregnancy or without meds. Trending this score tells us if treatments are working to lower your symptom severity and/or you are improving.

- [ ] Agree with HELP Score because: (reason optional)
- [ ] Disagree with HELP Score because: (reason optional)
- [ ] What if anything would you change in the wording of the questions and answers?
- [ ] What will you do differently after taking this survey? (Change meds, etc.)
- [ ] Other comments:

Last question! Check the options that apply.

- ☐ You may contact me about my answers or additional research?
- ☐ Please contact me when the study is published.
- ☐ Additional info about your pregnancy:
- ☐ Comments:

Time survey took **Action: Hidden Value**
Value: Populates with the **length of time** since the survey taker started the survey

Thank You!

Thank you for participating. **You may respond as often as daily to this survey**. If you want to return and finish or modify your answers, please return to this link: [survey("edit link")].

We plan to offer this tool to healthcare professionals so they better understand which patients need more aggressive care and can monitor the progress of treatments. If you would like a printable version of this survey tool, please click on this link.

DISCLAIMER:

Any suggestions or information provided should NOT be considered medical advice. Rather, it is intended to inform you of your options so you can discuss them with your health care providers. Proper treatment can only be determined after a complete exam and review of your history. Consult with your medical team before making any changes to your treatments, diet or lifestyle.

This survey is copyrighted by the HER Foundation. Any use other than personal for the care of HG is strictly prohibited. It may be shared with health professionals treating you or stored for your personal reference. It should not be used to guide or influence your medical treatment in any way. It has not yet been clinically validated.

For more info on HG and support, please visit our website @ http://www.helpher.org/info/top5Q.php. Join us on Facebook or follow us on Twitter @HGmoms. You will receive an email with your responses and an attached PDF to print or keep track of your responses. We appreciate your time and contribution to this research.

Confirmation Email

To: HG Research Participant ([question("value"), id="61"])

From: Kimber MacGibbon, RN (noreply@surveygizmo.com)

Subject: Your HG Survey Results

Action: URL Redirect
For more info on HG and support, please visit our website @ http://www.helpher.org/info/top5Q.php. Join us on Facebook or follow us on Twitter @HGmoms. You will receive an email with your responses and an attached PDF to print or keep track of your responses. We appreciate your time and contribution to this research.