

APPENDIX

From: Ashton Powell <Ashton.Powell@med.unc.edu>
 Subject: Patient Survey - Ataxia.org
 Date: October 11, 2007 6:15:47 PM EDT
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Request for help from Ataxia Forum members (Ashton)
 Posted: 2:08:37 pm on 8/16/2007 Modified: Never

Greetings,

My name is Ashton Powell. I am graduate student at the University of North Carolina at Chapel Hill currently engaged in a fellowship at Duke University at the Genome Ethics, Law & Policy (GELP) Center.

If you are unfamiliar with GELP, we are a research center that attempts to achieve societal consensus on how advances in genome science affect the health, individual rights, and distributive justice of the public. This summer GELP was asked by the US Department of Health and Human Services to provide background and case studies for the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS). More information regarding SACHGS can be found at the following link:

<http://www4.od.nih.gov/oba/sacehs.htm>

One topic GELP has been researching is to identify the affects, if any, of patents on clinical/patient access to genetic testing. My role in this report is to provide a case study for Spinocerebellar Ataxia, which as you may know has an interesting story regarding genetic testing.

For this case study, I feel I would be remiss if those affected by ataxia were not given the ability to have their voices and experiences included in our analysis. In particular, I am hoping to gain the perspective of those affected by ataxia on the role genetic testing has on their lives, their health, and their wallets.

With that in mind, I am writing to ask if you on this message board would be willing to aid me by answering some issues surrounding genetic testing. Using this forum, I hope a dialogue will form that in addition to providing me with your viewpoint will give the members of the SACGHS a dialogue they can view online.

I have already found many compelling stories on your forum regarding these issues, but creating a single accessible thread for the SACGHS will enable your voices to be heard as one. Committee members are not likely to search for keywords like "Athena" in your forum, they will probably only follow a single link.

Like on your forum, all persons who care to post a comment will remain anonymous. Also, please keep the identity hidden of MDs, or institutions that may have performed SCA tests without permission from Athena as legal action may be taken against them.

Some questions may reflect ignorance, but remember these are questions that may be asked by those completely unfamiliar with SCA, or ataxia in general.

While there are many issues that can be discussed about genetic testing, there are 11 topics in particular I am interested in:

1. Has your neurologist referred you for genetic testing for SCA? How long/how many visits did it take before this test requested? Do you feel this test should have been requested earlier? What was the diagnostic regiment you received prior to and after genetic testing?
2. Does your insurance cover genetic testing for ataxia? Does your insurance cover other, non-genetic testing for SCA?
3. Was/Is the out of pocket price for genetic testing prohibitive to your taking the test?
4. If you have had a genetic test for your ataxia, how did the result affect your treatment?
5. If you have had a genetic test for your ataxia, how did the result affect you feelings or understanding of your symptoms? What was the personal result of the genetic test?
6. For those who have had a genetic test, how many have come back negative? Did insurance tell you if they would cover the test before the results were received?
7. Have you tried to receive genetic testing outside of the US? Have you found labs other than Athena to provide SCA testing? (Please do not name them as it may lead to Athena taking legal action towards them). What were their prices like compared to Athena?
8. Have you been given any differential diagnoses (misdiagnoses) that genetic testing aided?
9. Do you feel that genetic testing for SCA is clinically relevant? How does genetic testing compare to other diagnostic methods?
10. Do you feel you have access to genetic testing? Do you think Athena's licensing monopoly on many of the SCA genetic tests alters the rate of prescription, and does this make the price too great for you to use them?

11. Have you ever used Athena's Patient Protection Plan, which claims to limit patient liability for the cost of a test to 20% as long as they meet certain insurance related criteria? Did Athena hold up their part of the bargain, and did this make the test accessible to you?
 The plan is described in brief here:

<http://www.athenadiagnostics.com/content/orderline/billing>

Thank you for your time.

I hope this makes a difference, even if just a small one,

Ashton Powell

Graduate Student

Curriculum in Neurobiology
UNC - Chapel Hill
Polleux Lab

Research Fellow
Genome Ethics, Law & Policy Center
Duke University

Re: Request for help from Ataxia Forum members ([dancingnoodle](#))
Posted: 3:44:47 pm on 8/16/2007 Modified: Never

I saw a Movement Specialist at UVA eight months after my initial diagnosis of ataxia. She suggested genetic testing, but my insurance would not cover it, since I don't have a family history of SCA. I cannot afford it out-of-pocket.

I think that Athena having sole ownership of this testing is unethical, and puts it out of reach of many people who may be helped by having this test. The Movement Specialist voiced her opinion on this as well and said it is so frustrating to her since the test could be easily done by more labs at less a cost, and then help her in diagnosing her patients.

Don't know if that helps at all, but that's how things have gone for me. I suppose if I felt the test would help cure me if I knew what I had, I would take out a loan to have it done, but since there are no cures at the moment, I don't see a reason for putting that financial burden on my family.

Cheryl

Re: Request for help from Ataxia Forum members ([Ashton](#))
Posted: 3:58:41 pm on 8/16/2007 Modified: Never

Thank you Cheryl,

Your post is exactly what we need.

If you don't mind, I have some follow up questions:

Did your insurance reject you when you asked for a genetic test, or are they never covered?

May I ask you if your Movement Specialist requested a specific SCA test or the Complete Ataxia Panel?

Did you attempt to enroll in Athena's Patient Protection Plan (PPP)? If so, were you accepted?

And forgive me if this is crass, but assuming you were to have the Complete Ataxia Panel performed and were enrolled in the PPP. would the 20% cost to you of \$1,460 (down from the \$7,300 list price) still place this out of reach?

Thank you again, Cheryl.

Ashton

Re: Request for help from Ataxia Forum members ([pawlayer](#))
Posted: 8:17:33 pm on 8/16/2007 Modified: Never

I didn't realize that only Athena Labs could perform this type of genetic testing. Why is this?

Re: Request for help from Ataxia Forum members ([Ashton](#))
Posted: 9:03:15 pm on 8/16/2007 Modified: Never

Hi pawlayer,

Thank you for your question.

As of now, Athena Diagnostics holds the licenses to use the patents for genetic testing of SCA-1,2,3,6,7, and EAOH. These comprise the genetic tests estimated 60-80% of known SCA mutations.

It is not clear which ones are exclusive only to Athena, they won't release that information. However, Athena has been known to send laboratories performing these patented methods letters. This action has caused several labs to stop performing the test; they now ship the sample to Athena.

As of now, Athena legally has the right to be the only company to perform the tests for the above SCA subtypes, they also have the right to sue anyone who performs them without obtaining a sub-license (which would be very expensive).

The question we are trying to ask is if allowing people to patent genes, methods to test for genes, or methods used for diagnostic genetic tests are keeping patients from using them.

Athena may be jacking up the price and controlling the market, but are they keeping patients from the test?

While any input on whether genes should be patented is welcome, my goal is to try and see if our current patent system affects patient care, not if patients like how that care gets to them (This is important as well but is another topic).

Thanks,

Ashton

Re: Request for help from Ataxia Forum members ([pawlayer](#))
Posted: 9:23:11 pm on 8/16/2007 Modified: Never

Do you know when the patent will expire? My mother used Athena in 1987, 20 years ago.

And from what I have read on this forum, many who suspect they might have some form of ataxia are unable to afford the cost of having the testing done.

I have not yet been tested for SCA 6. I don't know if my insurance will even cover it as I have not been referred for testing.

To answer one of your questions, I would pay for being tested for SCA 6 only, if my insurance did not cover it. However, it would be cost prohibitive for me for anything additional.

Athena set up a payment plan for my sister. She really could not afford it even though insurance paid 80% of the cost. I believe she is still paying for the testing.

Yes, it is unconscionable that other labs are prohibited from doing this. But then again, Botox offers pain relief for people suffering from back pain but it is cost prohibitive because insurance won't cover it, and the company that developed Botox has a patent as well.

So, is Athena preventing people from getting the test? How many responses would you need in the affirmative? There are just over 500 of us signed on to this forum.

Re: Request for help from Ataxia Forum members (Ashton)
Posted: 10:03:21 pm on 8/16/2007 Modified: Never

Hi pawlayer,

Thank you for your input, it too is very helpful. Athena does provide testing for SCA-6 individually and if you qualify for the Patient Protection Program, the price you will have to pay may go down to around \$100. It may be useful to give Athena a ring to check out the pricing and your eligibility.

I should be clear that Athena will not keep a patient from getting a test, but they may stop a specific lab from performing the test. They want to perform the test themselves. Athena will always give you the test if you have the means to pay for it.

But is the price, despite Athena's allegedly patient friendly payment plans, inhibitive?

The patents controlled by Athena are:

5,741,645 & 5,834,183 SCA-1 Filed: 1995, 1994

6,251,589 SCA-2 Filed: 1998

5,840,491 SCA-3 (MJD) Filed: 1995

5,853,995 & 6,303,307 SCA-6 Filed: 1997, 1999

6,280,938 & 6,514,755 & 7,118,893 SCA-7 Filed: 1998, 2000, 2003

7,119,186 EAOH Filed: 2002

They should each expire 17-20 years from their filing date, depending on the laws at the time.

You can find more info on each of these by searching for them at:

freepatentsonline.com/

I'm not sure how your mother's test fits into this picture, but the methodology used by me not have incorporated the same techniques at those above.

Ashton

Re: Request for help from Ataxia Forum members (Bobd)
Posted: 8:11:47 am on 8/17/2007 Modified: Never

I'll try to answer your questions in exactly the order that you gave them:

1. Yes, but I had to ask him to do it; he didn't "offer" it or suggest it. I requested this test after seeing him for about 4 years!! YES, he should have suggested this test MUCH earlier.
2. So far, my insurance has covered all the testing, but I haven't yet gotten the EOB on the genetic tests - and they were performed back in December of last year (9 months ago!). I haven't gotten any bill from Athena yet either.
3. Don't know yet (see above answer).
4. All results (results were back by March) were "normal" - no apparent genetic causes.
5. See above ...
6. See above ...
7. No, and No
8. No
9. Yes, if it would have revealed a genetic type that there was a treatment for. As it turned out, it did eliminate some possibilities, so that was a "positive" outcome of sorts.
10. Don't know how to answer this one.
11. No, and N/A.

HTH

Will be glad to answer any other questions you may have (that is, IF I can).

BJ

" Start every day with a smile and get it over with. " W.C. Fields

Re: Request for help from Ataxia Forum members (dancingpoodle)
 Posted: 10:18:54 am on 8/17/2007 Modified: Never

In response to your questions:

The insurance company said they wouldn't cover the genetic testing since there was no family history and the cost was so high.

The doctor wanted a complete panel and was willing to make a case to the insurance company for the need of the test, but because of no family history, there wasn't anything to base the argument on.

I wasn't aware of the PPP, but at this moment the cost would still be prohibitive since I've had to quit working full-time. Just like the insurance company, I guess I don't feel there is enough justification to pay for a test that has a high chance of coming back negative for anything specific.

I really can't complain about the insurance company as they have been great at paying for a lot of MRIs and other tests that have added up. I wonder if the overall cost of the test was reduced for the insurance companies as well, if they would be more willing to pay. After all, they have paid for numerous other tests that have come back negative. The odds of finding an answer with this \$7500 tests (and I was told it was closer to \$10,000) I suppose make the insurance companies less willing to cover it.

I also just have a personal issue with a company holding a patent for a test that could help more people if it was more readily available. The same as I have problems with companies holding a patent for a vaccine that could save lives and be made in greater quantities if not solely held by one company. I suppose that also makes me less willing to pay the money, but that's just a personal feeling. I'm sure many aren't even aware of the politics behind the testing. It's my own personal boycott, although not really effective, it does make me feel better knowing I'm not supporting a company who is in it for the money instead of the benefit of the people.

Cheryl

Re: Request for help from Ataxia Forum members (jonab)
 Posted: 1:42:53 pm on 8/17/2007 Modified: Never

Hi there Ashton. Would you please refer to the "Administration" section, where I responded to these questions from a post by Atilla. I intend to take advantage of the Athena Patient Protection Plan.

The problem, as I see it, other than the high cost, is that I have called my insurer to see if I am covered, and they have told me that I am covered, if it's "medically necessary". Well, I sure think that it's medically necessary, and I'm sure that my neuro does, also; but, will the Insurer think so? I'll let the group know how I make out. I'm going to have the Complete Ataxia Evaluation. I do not have a definite diagnosis yet, after 4 years, but I do realize the difficulty of this. The best we have come up with is "sporadic ataxia with nystagmus".

I found this also of interest. My neuro gave me a brochure re Athena, who I already knew about through my neuro, and told me to call Athena and have them call my insurer to see if I'm covered. Athena told me to have my neuro make the call. My neuro then told me to make the call. This is not the way the medical profession was meant to be administered, as we all know.

Thank you,
 Best,
 Jonab

Re: Request for help from Ataxia Forum members (Atilla)
 Posted: 3:25:33 pm on 8/17/2007 Modified: 4:07:54 pm on 8/17/2007

We posted all your questions under the Administration forum several days ago. There is even a link to it on the NAF homepage. The reason I started it there was that subjects "sink" rapidly in this forum and may become hard to find.
 ATILLA

Mrs. ATILLA still loves me

Re: Request for help from Ataxia Forum members (Ashton)
 Posted: 3:26:24 pm on 8/17/2007 Modified: Never

Here are several posts that were made from a duplicate of my initial questions. I didn't realize the duplication, so sorry for any confusion. If you could only respond to this thread, I'd appreciate it.

I've moved the other posts over to this thread so we can read them all at in one place.

Thank you for bringing this to my attention, jonab and thanks to Atilla, Rhana1, Christina and SunnyKay for your help!

Ashton

Re: Your input please (Rhana1)
 Posted: 10:02:57 pm on 8/15/2007 Modified: Never

1. yes, took 1 yr. i don't feel it should have been requested sooner. no diagnostic regimen before or after.
2. my ins does not cover genetic testing.
3. the cost was high, but I still had it done.

4. didn't affect treatment, as i have no treatment.

5. i was disappointed. As i have no diagnosis.

6. neg.

7. no

8. no

9. yes

10. yes

 Re: Your input please (clr)
 Posted: 10:09:30 am on 8/16/2007 Modified: Never

Hi there,

Here are some of my thoughts:

1. Yes. Three months after my neuro app't., Athena came directly to my house to do the blood draw. I was a bit surprised that my neuro was requesting the complete panel for me, since my mother had previously been tested for SCA1, SCA2 and SCA3 already...I was also sent for a swallowing evaluation and a brain MRI prior to genetic testing.

2. No, genetic testing is not covered by my insurance. Yes, they do cover standard diagnostic testing, such as MRIs, swallow evaluation, etc.

3. No, the pricing of the genetic testing was not prohibitive.

4. Since the results came up negative, my neuro and I agreed to monitor periodically via MRI and perhaps undergo any new genetic testing which becomes commercially available. And in the meantime, I decided to get a second opinion from an Ataxia specialist to confirm my partial diagnosis of SCA, type unknown. Additionally, we have discussed other potentials...

5. See above. Also, my extended family does not completely "buy" into the diagnosis of SCA, type unknown -- they still question past neurological diagnoses, particularly MS. It's very frustrating to me.

6. Yes, mine was negative.

7. No, I have not sought genetic testing outside of the US -- should I?

8. Once again, the genetic testing was supposed to put the MS diagnosis to rest for my family -- but that is still TBD, in some of my family's minds...even though I have tried to explain time and time again that the lesions presence and location is the deciding factor for our diagnosis, as I understand.

9. Yes, I feel that genetic testing for SCA is clinically relevant. However, and using my particular case as an example, other diagnostic methods such as neurological exam results, family history and MRI results are just as, if not even more, significant and revealing.

10. Yes, I have access to genetic testing.

Take care,
 Christina

 Re: Your input please (SunnyKay)
 Posted: 11:03:24 am on 8/16/2007 Modified: Never

Answering as a representative of my family...My Father had Ataxia and died Dec 2004:

1. Yes. Five Years. No. My father had Ataxia for a long time. My parents changed neurologists twice. The third neuro was excellent. He wanted to wait until the genetic testing had improved to a certain level. My family agreed. Prior:

Symmetrel, Aricept (d/c'd), physical therapy, home stretching program, cane to rollator to companion chair, participation in research studies. After: My father died within 2 weeks.

2. No. Yes.

3. Yes, but I arranged for my mother to get a payment plan.

4. Too late to have any affect as my father died. The testing was done more for our family than my father at that point.

5. The results were negative with one finding of "undetermined significance". Feelings of family were disappointment.

6. Basically all (see above).

7. No.

8. No.

9. Absolutely. Especially with known hereditary Ataxias.

10. Yes, but it causes financial hardship.

SunnyKay

Everyone Deserves A Great Doc!!!

 Re: Your input please (jonab)
 Posted: 12:13:12 pm on 8/16/2007 Modified: Never

Atilla:

Thank you. This is very timely and very important.

I.I first saw my neuro in 12/03. He referred me for genetic testing (Athena's Full Ataxia Evaluation) in 11/06. I did not have it done because of the uncertainty of insurance coverage for the \$ 7,500 cost.

No, I do not think the test should have been requested earlier.

I have changed insurance and have requested the same testing from Athena, this week, as the new insurance rep said that I was covered as long ass "it is medically necessary". I'll be happy if I only have to pay a 20% co-pay. I will not know, for sure, if I am covered until it's all over.

I have a tentative diagnosis of sporadic ataxia with nystagmus, but my neuro and I understand that this is not final.

2. See above. If the insurance company agrees that if is "medically necessary" then I am covered with a 20% co pay. Yes, I think that my insurance covers non genetic testig for SCA.

3. \$7,500 is prohibitive to me. However, I have no choice but to try anything out there, as my condition is deteriorating rapidly.

4. I have not had the genetic testing yet.

5. See 4. above. However, I expect that the tests will prove negative from what I have read of the experience of others.

6. I'll have to get back to you in several weeks, when the tests should be complete.

7.No, I have not tried outside the USA, simply because I hadn't thought of it.

8.No. I haven't had the genetic test yet.

9.Yes. I think that genetic testing for SCA is "the future". I just don't know what there is for us poor.....sho may not have any genetic basis for our "ataxic disorders", as Dr. Perkamn calls them.

10. Yes, I have access to genetic testing thru my neuro. I only know of Athena labs, though.

Thank you, Atilla.

PS My neuro and I agreed that I will see Dr. Perlman, UCLA. Yea! (See my earlier posts)

Best,
Jonab

Re: Request for help from Ataxia Forum members (Rhana)
Posted: 8:14:32 pm on 8/17/2007 Modified: Never

I also already answered these questions, under the Admin section. But if I can be of further help, let me know.

Rhana

Re: Request for help from Ataxia Forum members (pawlayer)
Posted: 12:00:41 pm on 8/18/2007 Modified: Never

Here's the response I got from Athena:

"Thank you for your inquiry. All testing must be ordered by a physician. Athena Diagnostics offers a test called the Familial Mutation Analysis Evaluation. This test is available for family member of patients that have previously been tested by Athena and received a positive result. We will evaluate only the mutation detected in the proband. If we bill a commercial insurance plan with which Athena is not a contracted provider the Patient Protection Plan would limit the out-of-pocket expense to \$117. If we are to bill an insurance plan with which we are a contracted provider, the normal co-pay and deductible obligations would apply. Would you need to contact the insurance directly for that information."

I won't be able to fully participate in your questionnaire until I have been tested. I hope this will be ongoing as I will not even meet with the neurologist until November.

Patricia

Re: Request for help from Ataxia Forum members (Ashton)
Posted: 4:19:06 pm on 8/20/2007 Modified: Never

Hi Rhana,

Does your insurance not cover any genetic testing or just the SCA testing?

Where you able to enroll in the Patient Protection Program that Athena has?

If the Complete Ataxia Panle were now \$1500 out of pocket, would you be willing or able to have it performed?

Thanks you for your help,

Ashton

Re: Request for help from Ataxia Forum members (SunnyKay)
Posted: 8:21:00 pm on 8/20/2007 Modified: Never

Ashton,

As far as I know, Medicare does not cover SCA testing. My mother requested that Athena NOT BILL MEDICARE because she wanted to keep the results PRIVATE for numerous reasons. That is why a payment plan was arranged instead.
SunnyKay

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Re: Request for help from Ataxia Forum members (Ashton)
Posted: 8:42:28 pm on 8/20/2007 Modified: Never

As an addition to this topic, how many of you feel the need to get a diagnosis for SCA outside the knowledge of your insurance carrier?

It appears the pricing Athena gives assumes that insurance will be involved and will pay the massive price of the tests. If insurance REFUSES to pay, then Athena's Patient Protection Plan will cover most of the costs. However, if a patient

It appears the pricing Athena gives assumes that insurance will be involved and will pay the massive price of the tests. If insurance REFUSES to pay, then Athena's Patient Protection Plan will cover most of the costs. However, if a patient CHOOSES not want to use insurance, it then they have to take the entire cost themselves.

Unfortunately this leaves one heck of a bill.

Is the genetic test the only diagnostic test you all choose to take outside of insurance?

Do you fear discrimination from the insurance companies?

Have any of you encountered discrimination from an insurance company due to a genetic test?

Thank you,
Ashton

Re: Request for help from Ataxia Forum members (Ashton)
Posted: 9:40:05 am on 8/21/2007 Modified: Never

Re: Your input please (mmhogan)
Posted: 10:30:43 am on 8/18/2007 Modified: Never

1. No because the results for other members of my family with Ataxia have shown negative to all known SCA's. No, because it would not be cost effective to spend money testing for something that will almost certainly show negative as well. Diagnostic regiment included neurological exam and MRI, in depth record of family history.
2. Yes, we are an active duty military family...health insurance is free.
3. No
4. N/A
5. N/A
6. N/A
7. No
8. Previously misdiagnosed w/ eye problems due to altitude.
9. Yes. It's the only way to know if you have one of the known testable Ataxias.
10. Yes.

Mary

Re: Request for help from Ataxia Forum members (clr)
Posted: 9:59:16 am on 8/21/2007 Modified: Never

Hi Ashton,
Isn't this where GINA may come in handy, when finally passed?

Take care,
Christina

Re: Request for help from Ataxia Forum members (Ashton)
Posted: 10:42:45 am on 8/21/2007 Modified: Never

Hi Christina,

Well, Genetic Non-discrimination laws have been brought up in congress every year for the past ten years, but none have yet to pass. This year looks like it may pass, but you never know. There are many states that have passed nondiscrimination laws regarding genetics, but a federal law is way past due.

It would do nothing but help get this passed if there is more evidence of how patients use genetic testing (among other medical treatments) based upon real or perceived risks of discrimination by their insurance carriers.

It appears that in the case of SCA, there are quite a few patients who want to know the result of the test without their insurance knowing. I can only assume this is due to a fear of what an insurance company may do to them or their family members with this information.

Any information/stories about the "risks" of diagnosis would be quite interesting.

Thanks,
Ashton

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Re: Request for help from Ataxia Forum members (SunnyKay)
Posted: 1:02:14 pm on 8/21/2007 Modified: Never

SunnyKay here again...See above...

My mother not only did not want the health insurance company/Medicare to know about possible SCA results, she did not want to apply for a handicapped license plate with a diagnosis of some form of Ataxia either. This is in addition to other things she did to keep anyone from the government or any other unnecessary place from finding out about my Dad's medical history (which of course becomes OUR, her children's, family medical history for life...life insurance, Long Term Care, disability, employment, health insurance, etc., etc.).

SunnyKay

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Re: Request for help from Ataxia Forum members (marjorieve)

Posted: 2:53:07 pm on 8/21/2007 Modified: Never

Ashton-

1. My research neuro at Johns Hopkins asked that I request the test from my local treating neuro, who was happy to comply. I was diagnosed with "An hereditary form of Cerebellar Ataxia" based on my history and the physical exam. I was negative for all but an SETX mutation of unknown significance after the Athena tests.
2. It paid 80%, so I had to pay like \$1,500.
3. Yes.
4. I suppose it didn't. My neuro pretty much just documents my degeneration and I have to find my own rehabilitation techniques. I tell him and he says "Hm. That's a good idea."
5. I felt a lot better having a clearer picture of my Ataxia. It also greatly helped my research neurologist.
6. There wasn't a problem with my insurance. All but the SETX mutation were negative.
7. No.
8. I think for awhile neurologists treating my family were thinking we probably had SCA6- it's helped a lot to be able to rule that out.
9. SCAs vary too much to rely on anything other than genetic testing. And unless we separate out the different genetic mutations, how could we ever hope to fix them?
10. Definitely. If more ataxians could be genetically tested, I think it would further Ataxia research. The cost and inavailability keeps a lot of people from digging deeper into the cause of their neurological problems.
11. I think so, but my insurance plan was very good, so I think that was mainly why I didn't have many problems dealing with them.

If there's anything else I can do to help, Ashton, just say the word. I live in Roanoke, which is pretty close to you.

-Marjorie

"Onward we stagger, and if the tanks come, may God help the tanks."

—William O. Darby

Re: Request for help from Ataxia Forum members (marjorieve)

Posted: 2:54:00 pm on 8/21/2007 Modified: Never

Ashton-

1. My research neuro at Johns Hopkins asked that I request the test from my local treating neuro, who was happy to comply. I was diagnosed with "An hereditary form of Cerebellar Ataxia" based on my history and the physical exam. I was negative for all but an SETX mutation of unknown significance after the Athena tests.
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-Marjorie

"Onward we stagger, and if the tanks come, may God help the tanks."

—William O. Darby

Re: Request for help from Ataxia Forum members (Happy Christian)

Posted: 12:56:30 am on 8/22/2007 Modified: Never

I AM NEW TO THIS FORUM. I JUST RECENTLY LEARNED ABOUT NAF. I DON'T WANT TO APPEAR STUPID, BUT WHAT IS ATHENA ?

I HAVE NOT HAD ANY GENETIC TESTING, BECAUSE I KNEW RIGHT FROM THE BEGINNING OF MY DIAGNOSE THAT MY INSURANCE WOULD NOT COVER GENETIC TESTING. I WAS DIAGNOSED WITH SPINOCEREBELLAR DEGENERATION IN 2002. I HAVE LIVED WITH ATAXIA SINCE MY EARLY 30'S (AND I AM NOW 64) BUT MY PREVIOUS DOC (BEFORE 2002) WAS ONLY LOOKING FOR MS.

WHERE IS THE GENETIC TESTING DONE? I LIVE IN NORTH EAST OHIO

ANSWERS TO MY QUESTIONS WOULD BE APPRECIATED. THANK YOU

HAPPY CHRISTIAN

Re: Request for help from Ataxia Forum members (pawlayer)
Posted: 9:11:14 am on 8/22/2007 **Modified:** Never

Hi and Welcome:

Athena is a lab that conducts the testing for diagnosing diseases, more importantly, in this instance the testing for the different types of ataxias. I believe it is located in Mass., but it operates all over the country (my understanding). They have a web site which will give you a lot more information. Just Google Athena Diagnostics, and its official site will come up. They have a lot of information about the company on its site.

Re: Request for help from Ataxia Forum members (Ashton)
Posted: 11:05:17 am on 8/22/2007 **Modified:** Never

Hi Happy Christian,

Welcome to our discussion. Don't feel stupid at all, especially when our discussion is to ask whether the system we are working with is stupid.

As pawlayer said, you can find much information regarding the genetic testing Athena offers, and has legal rights to be the sole provider for at:

athenadiagnostics.com

Some of the issues we are attempting to figure out are if the prices Athena uses for these tests, which are expensive even if done at cost, are preventing patients from using them according to best medical practice. The real goal is to ask whether current patent law, which allows them to dictate price is affecting patient access to the tests.

There is an interesting relationship however between Athena, insurance companies, and MD/patients that is coming from this. Athena charges a large sum for testing, but has a Patient Protection Program (PPP) that limits the patient's liability to 20% of the total cost of the test. This brings the cost of the test down to what is generally the co-pay required if you insurance decides against coverage for the test.

However, it appears that many of you are not attempting to see if you are eligible for the PPP because you already know your insurance does not cover these tests. I am not 100% sure, but you may still be eligible for the reduced rate from Athena, it wouldn't hurt to ask.

The other interesting topic is that many patients choose to keep insurance out of the picture for a variety of personal reasons, but this ensures the price of testing will remain the massive \$7,300. In other words, the requirement of insurance has reared its ugly head in this discussion.

Thanks for any input you have,

Ashton

Re: Request for help from Ataxia Forum members (Poolgirl)
Posted: 3:19:33 am on 8/23/2007 **Modified:** Never

Hi Ashton,

Answers to questions:

1. Yes. several years after first symptoms and ordered by 6th Neurologist I saw (to be fair to others, my exam changed significantly during that time).

2. Insurance covers all my testing

3. see #2

4. No

5. Ataxia panel negative. Only real benefit for me was less worry that I might have passed something on to my children (although I am well aware that just means I don't have one of the already identified genetic ataxias).

6. Tests negative

7. No

8. No

9. I feel testing is indicating if the history strongly suggests the test will be positive. Having an ataxia specialist narrow down the most likely disease may help cut down on blindly running full ataxia panels. I am not sure if it is more cost effective to run specific test or the whole panel. Sometimes labs bundle tests and it ends up being cheaper to run the panel(maybe you already answered this but if not, could you please address running for example, 3 variants versus panel. I personally feel the other tests to look for treatable causes of ataxia are more important and should be done first.

10. tests were covered

11. tests were covered

Note: I had the genetic tests done at a very vulnerable point in my work up and thankfully they were negative. Given the implications a positive test could have on my children, had I been thinking clearly, I would not have done the test or would have considered paying for them myself to avoid having them on record. I will not do any tests that become available in the future unless one of my children specifically requests it be done to help guide them if/when they are thinking of having children and if so, I would probably do it off the record. I have no problems with my medical insurance but my personal interaction with my disability company has made me very cynical about trusting any "insurance" carrier to " do the right thing".

PG

Re: Request for help from Ataxia Forum members (Atilla)
Posted: 9:06:30 am on 8/23/2007 **Modified:** 1:17:58 pm on 8/23/2007

If you haven't already, you may want to contact Dr. Marsha Nance. She is the NAF "expert" on genetic testing.
ATILLA

Mrs. ATILLA still loves me

Re: Request for help from Ataxia Forum members (rrrose)
Posted: 2:03:08 pm on 8/23/2007 Modified: Never

Ashton...I have SCA6 which was confirmed by testing at Athena Labs. I will try to answer your questions.

1. My neurologist suggested testing after my first visit in 2004. He is a movement specialist that I was referred to by another neurologist who suspected some type of dominant Ataxia. I sought out treatment after experiencing similar symptoms to my mother, who at that time had been told she had "some troubling signs" on an MRI, but was not offered any genetic testing. Her neurologist told her it was very expensive and it would not change anything in her prognosis as there was nothing that could be done for her. I had a full panel of tests done and was initially told the results were inconclusive. Athena requested another blood sample to re-run the tests, but for some reason my doctor failed to communicate this to me until March of 2007. He then sent new samples to Athena (at no additional cost to me) and I received a definite diagnosis of SCA6.
 2. My insurance company did not cover the cost of the test. The cost to me was \$2500. They told me at the time it was because Athena was not one of their preferred providers. I was required to pay the entire amount upfront, directly to Athena Labs.
 3. No, but I only paid \$2500, not the \$7500 mentioned in the posts on this forum.
 4. Only that I stopped the worrying about gluten, and the possibility that I might have gluten ataxia.
 5. Having a definite diagnosis is helpful in some ways, as I tend to focus my research, but troubling in other ways with respect to my children. They know I have the same thing as their grandmother, but the whole question of when to tell them they can be tested is very difficult. How do you tell three young men 20,18 and 16 with no symptoms, to have testing done that might change the course of their life decisions? I'm not sure I have the answer to that.
 6. My initial results were inconclusive, but eventually were confirmed as SCA6. I had to pay for the tests out of pocket.
 7. No
 8. No, just confirmation when the final results came back.
 9. Yes. Because I now have a definite diagnosis, the other members of my extended family who have been misdiagnosed, can request testing be done for SCA6 only, at a greatly reduced price. Many of which, could not otherwise afford the tests.
 10. Yes. Just a little hiccup with the results, but appears to have been on the part of my neurologist, not Athena.
 11. N/A
- I hope this information is helpful. Thanks for your efforts.
RRose

Re: Request for help from Ataxia Forum members (jonab)
Posted: 5:19:41 pm on 8/23/2007 Modified: Never

Hi RRROSE;

Just one small point of possible clarification. The Athena Complete Ataxia Evaluation is more than one test, and cost about \$7500. It may be that the \$2500 that you mentioned was for one test only.

Best,
Jonab



Re: Request for help from Ataxia Forum members (SunnyKay)
Posted: 7:37:52 pm on 8/23/2007 Modified: Never

Jonab and All,
When my Dad was tested in the fall of 2004, there were less available tests in Athena's Complete Ataxia Panel, and the cost was much less than \$7500 as I recall...
SunnyKay



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Re: Request for help from Ataxia Forum members (Steph74)
Posted: 10:38:28 pm on 8/23/2007 Modified: Never

1. No - I got tested on my own and went to a genetic counselor, after my father was diagnosed, I'm currently asymptomatic. It took me almost 2 months to get my results, since Athena had to run the test twice due to a lab "error". My genetic counselor failed to tell me, so I showed up awaiting the results and then was told I would have to come back again.
2. Yes BCBS - but I paid for it out of pocket so they were unaware.

2. Yes BCBS - but I paid for it out of pocket so they were unaware.

3. No

4. I was shown to have the expansion for SCA1, but no treatment since I have no symptoms as of yet.

5. I was pretty upset, but I knew I had a 50% chance.

6. N/A

7. No

8. No

9. N/A

10. N/A

11. No

* I'm not that happy with Athena - first it took FOREVER to get my results, and second, I asked them to run my father and I's blood next to each other (we had gotten our samples done years apart) so I could look at repeat differential - I even offered to pay, but they refused.

Re: Request for help from Ataxia Forum members (Ashton)
Posted: 7:57:15 pm on 8/24/2007 **Modified:** Never

Hi Steph74,

Thank you for helping me out with this project. I'm sorry to hear about your results considering you are asymptomatic. I hope your experiences will help us move towards some true cures in the near future.

If you don't mind, may I ask you some specific questions about your testing?

How much did the single SCA-1 test cost you?

Do you consider this price reasonable, especially with insurance not being part of the equation?

Since your father been tested by Athena before and came back positive, were you given a discount?

What do you feel, or know would happen with your insurance if they were involved in this testing?

Thank you Steph,

Ashton

Re: Request for help from Ataxia Forum members (rrose)
Posted: 8:08:26 pm on 8/24/2007 **Modified:** Never

Hi Jonab,

Actually I did have the complete Ataxia panel done. I was under the impression that I was covering the entire cost, but with the information I am reading in this forum, my insurance company may have in fact paid for a portion of it. My testing was done several years ago, and at the time my neurologist was not hopeful that insurance would cover it. But possibly they did. That would be a surprise!

Re: Request for help from Ataxia Forum members (Steph74)
Posted: 8:53:41 pm on 8/24/2007 **Modified:** Never

1) Somewhere around \$600 (I really can't remember specifics) - this was in 2006.

2) Yes, I would consider this price reasonable.

3) No, I wasn't given a discount.

4) I have not experienced any negative results with BCBS. They are now aware of my status of SCA (even asymptomatic) because I had a child and disclosed it during my pregnancy, due to risks related to labor/delivery. There has been full payment for everything. I even had my child tested in utero for SCA and they paid for it in full. I've also been to an ataxia neuro to make sure I wasn't showing any symptoms and they paid for that consultation as well.

Re: Request for help from Ataxia Forum members (Ashton)
Posted: 9:05:45 pm on 8/24/2007 **Modified:** Never

Hi Marjorie,

Thanks for your input,

I have a question for you that is not as much about the pricing of the tests, but the human desire to learn more about themselves.

Before medical research was able to differentiate between the genetic subtypes of SCA, the diagnosis for many of the "ataxians" would have been Olivopontine cerebellar atrophy (OPCA). Later the classification of these hereditary ataxias was

divided into autosomal dominant cerebellar ataxia classes (ADCA) I, II, and III. We now know that ADCA I encompasses SCA1, 2, and 3, ADCA II is SCA7, and ADCA III is SCA4, 5, 6, and 11.

Do you feel that your desire to search for a diagnosis would have been quenched if OPCA was your diagnosis and research was where it was 20 years ago? Would that satisfy you today?

If a new SCA designation is identified genetically do you think it would change any satisfaction you may have with this hypothetical diagnosis of OPCA? Does the search begin anew whenever there is a possible refinement of diagnosis?

Anyone else who has any thoughts on this, please feel free to write. In some ways this may help describe whether the patient demand for genetic introspection may coax people into paying fees for tests that well above their true value.

Thanks Marjorie,
Ashton

Re: Request for help from Ataxia Forum members (Ashton)
Posted: 9:18:24 pm on 8/24/2007 Modified: Never

Hi Poolgirl,

Thanks for your answers, they are quite helpful.

Did you have any co-pay for the test?

You write a bit about cynicism toward insurance companies and a positive result (a feeling shared by many of us I'm sure!)

The standard fear is that a company may now drop you or make it difficult for your children if the result is positive, but does an insurance company treat you any differently if you come back negative? Have you noticed a difference in how responsible an insurance company feels in regard to covering treatment for an undiagnosed vs. negatively diagnosed client?

As for different panels for the tests, I agree it would make sense for a company to offer "combo meals" depending on common symptoms or diagnostic procedure. I will discuss it in my report.

Thanks for the ideas,
Ashton

Re: Request for help from Ataxia Forum members (marjorievs)
Posted: 10:43:59 pm on 8/24/2007 Modified: Never

Ashton-

My granddad and his brother were originally diagnosed with OPCA. The general feeling in my family for the past 200+ years we've passed this along is that you can't do anything about it, so why bother thinking too much about it. But I myself feel driven to find out as much about it as I can.

First when I was diagnosed and then more so as my symptoms have worsened. I've felt more and more helpless to fight what is happening to me. I like to at least be somewhat knowledgeable about the disease that's wringing the freedom out of my lives, since there's very little I can do to fight it. There's no surgery I can have, no experimental drugs, and rehabilitative techniques will only slow things down, not cure me. Sometimes it seems like knowledge is all I can depend on.

So yes, I think I will continue to be dissatisfied and will continue to get all the testing I can to find out more about my Ataxia.

-Marjorie

"Onward we stagger, and if the tanks come, may God help the tanks."
—William O. Darby

Re: Request for help from Ataxia Forum members (smilties5)
Posted: 10:16:52 am on 8/29/2007 Modified: Never

I was diagnosed in June 2006, I am 54. I talk to a lady in Georgia who's had ataxia for 20 years or more. So I asked my dr (neurologist at Jefferson) if it was to my benefit that I was diagnosed later in life, and he said yes.

Any comment or suggestions?

Beverly Smith

Re: Request for help from Ataxia Forum members (SunnyKay)
Posted: 7:15:53 pm on 8/29/2007 Modified: Never

Ashton,

My mother donated my father's brain for research "to help the future". I personally want to know an exact diagnosis as soon as it is determined, discovered, named, etc. We were given 2 potential diagnoses but they were not any identified SCAs and I personally disagree with them. (They seem to be even more rare than some of the SCAs!) I'm a family doc, and they just don't match what my Dad had.

SunnyKay

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Re: Request for help from Ataxia Forum members (greekmom81)

Posted: 2:26:23 pm on 9/3/2007 **Modified:** Never

Hi Ashton,

I don't know if my story qualifies for your study, but you can be the judge. Well after we came back from a long vacation to Europe, I noticed that I couldn't balance on my right foot. I mentioned to our doctor who assured me that it happens to everybody one time or another. I was 49 years old. I let it go and I mentioned again after a year because it wasn't getting any better. He sent me to a neurologist who after examined me, and a MRI, he found nothing wrong. To make the long story short after him I visited a lot of other neurologists who they suspected Parkinson or MS but nothing concrete. In 2000 I went to UT SOUTHWEST where with a MRI I was diagnosed with 'sporadic OPCA'. Since we didn't know what was it, we didn't panic even though he told us there is no cure for it.

Since then I saw a lot of doctors in Houston, Galveston, Dallas, but none of them suggested genetic testing. I participated in a clinical trial in NIH for IVIG but even though I got the right medicine they stopped the trial because the drug wasn't doing any good to the majority of the people. I tried acupuncture, gluten diet, vitamins, chiropractor, alternative medicine, without success. So I am going to try to answer your questions as good as I can.

1. NO
2. NO/NO
3. YES
4. IT DEPENDS (A LOT OF STUDIES ARE ONLY FOR GENETIC TYPES)
5. I DON'T KNOW. I HAD NO SYMPTOMS
6. N/A
7. NO, NO
8. A LITTLE ABOUT MS OR PARKINSON
9. YES, I THINK IS MORE ACCURATE
10. YES
11. NO, AND I DON'T THINK I AM QUALIFY IF THE INS. CAN NOT USE THE RESULTS AND DROP ANY OF US GREEKMOM81

Re: Request for help from Ataxia Forum members (chvann)

Posted: 11:00:58 pm on 9/3/2007 **Modified:** Never

1. Has your neurologist referred you for genetic testing for SCA? Yes

How long/how many visits did it take before this test requested? This was a new neurologist but he did it on the first visit. It had never been done before.

Do you feel this test should have been requested earlier? Probably, but it was not until 16 years ago.

What was the diagnostic regiment you received prior to and after genetic testing? As a child I had spinal taps, x-rays, brain scans, touch-your-finger-to-your-nose-with-your-eyes-closed, stand with your eyes closed, walk this line, etc. type of tests but it had come down to 'do you think it has gotten worse' questions as an adult. Since the tests could not pinpoint what kind of ataxia it is, the treatments were megadoses of vitamin E, coQ10 and suggestions that 'swimming will help your muscle tone so you will have more control' type of treatments.

2. Does your insurance cover genetic testing for ataxia? Yes

Does your insurance cover other, non-genetic testing for SCA? MRI, and physical therapy to train me to use a walker and now a scooter.

3. Was/is the out of pocket price for genetic testing prohibitive to your taking the test? I only paid for the office visits but it has been years since the last test.

4. If you have had a genetic test for your ataxia, how did the result affect your treatment? No effect because it did not pinpoint the KIND of ataxia.

5. If you have had a genetic test for your ataxia, how did the result affect you feelings or understanding of your symptoms? No effect, nothing new.

What was the personal result of the genetic test? No result

6. For those who have had a genetic test, how many have come back negative? It is definitely not something else.

Did insurance tell you if they would cover the test before the results were received? No

7. Have you tried to receive genetic testing outside of the US? No

Have you found labs other than Athena to provide SCA testing? No
(Please do not name them as it may lead to Athena taking legal action towards them).

What were their prices like compared to Athena?

8. Have you been given any differential diagnoses (misdiagnoses) that genetic testing aided? No, by the time genetic testing was done I was grown and I was diagnosed at age 10

9. Do you feel that genetic testing for SCA is clinically relevant? Yes, ataxia has terrible consequences. If they can find the cause and fix it, many people would be spared much suffering.

How does genetic testing compare to other diagnostic methods? I don't know, I'm not a doctor.

10. Do you feel you have access to genetic testing? I've been tested several times in the last few years.

Do you think Athena's licensing monopoly on many of the SCA genetic tests alters the rate of prescription, and does this make the price too great for you to use them? No

11. Have you ever used Athena's Patient Protection Plan, which claims to limit patient liability for the cost of a test to 20% as long as they meet certain insurance related criteria? Insurance always paid because I have a definite diagnosis.

Did Athena hold up their part of the bargain, and did this make the test accessible to you? No problems

Re: Request for help from Ataxia Forum members (lacams)

Posted: 2:04:18 am on 9/5/2007 **Modified:** Never

1. Has your neurologist referred you for genetic testing for SCA? YES How long/how many visits did it take before this test requested? ONGOING, AS NEW TESTS WERE DEVELOPED Do you feel this test should have been requested

- earlier? YES What was the diagnostic regiment you received prior to and after genetic testing? THE GENERAL SCA DX WAS CLEARLY INHERITED
2. Does your insurance cover genetic testing for ataxia? SOME Does your insurance cover other, non-genetic testing for SCA? YES
3. Was/Is the out of pocket price for genetic testing prohibitive to your taking the test? YES, ABSOLUTELY!
4. If you have had a genetic test for your ataxia, how did the result affect your treatment? ONLY NEGATIVE RESULTS SO FAR, BUT MANY TESTS HAVE YET TO BE DONE
5. If you have had a genetic test for your ataxia, how did the result affect you feelings or understanding of your symptoms? FRUSTRATION What was the personal result of the genetic test? THE FEW TESTS DONE SO FAR WERE ALL NEGATIVE
6. For those who have had a genetic test, how many have come back negative? SEVEN Did insurance tell you if they would cover the test before the results were received? PARTIALLY
7. Have you tried to receive genetic testing outside of the US? NO Have you found labs other than Athena to provide SCA testing? NO (Please do not name them as it may lead to Athena taking legal action towards them). What were their prices like compared to Athena? I DON'T KNOW. IT'D BE NICE IF SOMEBODY WOULD SLIP AN ANONYMOUS REFERRAL INTO THIS FORUM.
8. Have you been given any differential diagnoses (misdiagnoses) that genetic testing aided? NO
9. Do you feel that genetic testing for SCA is clinically relevant? TOTALLY! How does genetic testing compare to other diagnostic methods? IT WOULD BE AWESOME, ESP SINCE WE HAVE KIDS AND OTHER RELATIVES WHO COULD BE AFFECTED
10. Do you feel you have access to genetic testing? NOT AT THE MOMENT Do you think Athena's licensing monopoly on many of the SCA genetic tests alters the rate of prescription, and does this make the price too great for you to use them? ABSOLUTELY!
11. Have you ever used Athena's Patient Protection Plan, which claims to limit patient liability for the cost of a test to 20% as long as they meet certain insurance related criteria? THEY ARE CURRENTLY DEMANDING AN EXHORBITANT COPAY UP FRONT Did Athena hold up their part of the bargain, and did this make the test accessible to you? IT PROBABLY WILL BE INACCESSIBLE. ^{1/4}
The plan is described in brief here:

<http://www.athenadiagnostics.com/content/ordering/billing>

Re: Request for help from Ataxia Forum members (jonab)
Posted: 1:01:16 pm on 9/9/2007 **Modified:** Never

Hi there Ashton:

I have already responded to your questionnaire, but I have not completed the Athena testing yet. Presently, my blood samples are at Athena being tested and I expect the results in a another week or two. They are doing the Complete Ataxia Evaluation (Panel).

I did want to inform you though that Athena said that I was not eligible for the Patient Protection Plan since they have a contract with my insurance company.

I can only hope that this means that I'll only be responsible for the co-payment. I'll let you know the end results.

I hope that your system can handle piecemeal data like this.

Best,
Jonab

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There are currently 600 members registered on National Ataxia Foundation - ENAF BB.