Testimonials for the Effectiveness of Anti-Viral Treatment for Meniere's Disease
Compiled by PapaJoe on Menieres.org
This document can be found at:
http://www.papadisc.com/Menieres_Efficacy_AntiViral.pdf

The web site http://www.menieres.org/ hosts a user forum for people suffering from Meniere's Disease and similar vestibular disorders. It is one of many such sites on the internet. The software allows a user to post a poll to the message groups for forum members to vote on if they wish. Recently, I posted this poll, at the Menieres.org "Living Room" forum. The poll was active for seven days and 27 people responded by taking the poll. There was a one vote per forum member restriction on the poll, and members were not able to change their vote.

Here is the poll text:
Please answer the poll and also reply and tell us which anti-viral medication you are taking, or have taken in the past.

I'd like to know how long you had MM before taking the anti-virals, and whether or not you know that you have nerve damage. I'm especially interested if they didn't work or caused unacceptable side effects.

I'll be posting a long message on the weekend listing scientific studies concerning MM and viruses. I want to put together a document with those results and the results of the poll (testimonials) that patients can use to help convince their MD to consider prescribing anti-virals if you so choose.

I suspect that Herpes is related to MM. I do not necessarily think it is the only cause of MM. There may be other viruses, and bacteria (at least in the form of Lyme Disease) can cause MM-type symptoms and may be mid-diagnosed as MM. HenrySullivan and others think that spinal mis-alignment may cause it in some people.

JohnOfOhio's plan has helped a lot of people, but the plan, along with Gent or Dex injections, diuretics, betahistine, valium, etc, and surgery, are all attempts to control the symptoms and not solve the root problem, though I will leave open the possibility that the JOH plan may address the cause as well.

When I compile the testimonials, I'll leave off the screen names for privacy.
Thanks!

Here are the poll choices:

Two months and it helped a little
Two months and it helped a lot
Two months and I got worse
Two months and I couldn't tell
I stopped before two months due to side effect
I'm taking but it's too soon to tell

Of the 27 people who took the poll, 14 (51.9%) reported a substantial improvement with either Acyclovir or Famvir for long term therapy using maintenance doses between attacks. No one got worse, two had side effects and seven have just recently started taking them.

Here are the results:

- Two months and it helped a little: 1 (3.7%)
- Two months and it helped a lot: 14 (51.95%)
- Two months and I got worse: 0
- Two months and I couldn't tell: 3 (11.1%)
- I stopped before two months due to side effects: 2 (7.4%)
- I'm taking but it's too soon to tell: 7 (25.9%)

Total Voters: 27

Here are some comments from users on the forum. Users were able to, and did, make multiple comments.

I am now on day 19 of a 21-day trial of acyclovir, 800 mg x 3/da. My ENT told me to have an audiogram before he would prescribe any more. Here are the results of today's test on my MM (right) ear compared to one taken just 4 weeks ago. Quite significant! Even better was that my word recognition went from 44% to 84%, so the new HA I got this afternoon works just fine. Other significant changes - No more pain and itching in that ear, No hyperacusis, Almost no fullness--it still comes and goes a bit, No brain fog.

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I took antivirals for treatment of cochlear hydrops. My symptoms included hearing distortion, low frequency hearing loss, autophony and constant loud tinnitus. Originally I took acyclovir for about a month by my family dr after the neurotologist ran out of things to try. The family dr had suspected a virus was involved in my case. It helped a lot starting around day 4 and 5 but it was not an instant or complete cure. It was the first thing that
had helped in 9 months of consulting a neurotologist. The tinnitus was almost eliminated, the autophony greatly reduced, the hearing loss did not progress further and the distortion was greatly improved. I followed up with allergy treatment and a course (3 month) of famvir prescribed by a dr at House Ear Clinic. After 2 1/2 years my hearing loss is now borderline normal, my distortion, autophony and tinnitus almost gone. I still have remnants of my hearing disorder but the improvement from these treatments has changed the quality of my life dramatically. Although I have had some fluctuations in symptoms, never since I first took the acyclovir have my symptoms returned to anywhere near as bad as they were those first nine months before.

Acyclovir, lived with MM 21 years before starting anti-virals. 90% success rate. No side effects.

I've been taking it for just about a month and it does seem to be helping a lot. I have cochlear hydrops so just hearing loss/tinnitus/fullness/hyperacusis and all these symptoms have nearly gone away with some tinnitus remaining - and my hearing, though in the normal range, isn't quite what it used to be. I have 2 more months to stay on it before my prescription runs out.

Started taking it in Aug. Am now on maintenance dose. Also take serc 3 times a day. Don't know if I have nerve damage. Have been diagnosed since April. Have been having rapidly deteriorating hearing since 2007. No side effects for me. Have been feeling a lot better. No vertigo, no spins, (knocking wood), Last audiogram in Oct. showed some increase in hearing. Less tinnitus, but it is still there on some days.

Valtrex - started over 4 1/2 years ago and still take a maintenance dose. This along with other meds, exercise, balance therapy, diet and a lot of hard work got me my life back. No side effects from the valtrex. But it did ease several symptoms.

I'm still taking my maintenance dose of 400 to 800 mg daily. I have stopped it for days and up to a week without any symptoms returning. But I still take it just in case. I'm still at a 90% improvement of symptoms from when I had my last flareup in February.

There is not a poll choice that describes my history with anti-virals. I took it for one month along with lysine when my hearing was cratering. I had no side effects but it did no good. My ENT and his nurse practitioner (she works for 3 ENTS, has a very strong interest in MM and appears more knowledgable about inner ear problems than many MDs) said they felt it was critical to begin the anti-virals very early if they were to have an impact. Once the damage is done, they both suggest, the anti-virals or lysine could do little.

Regarding the poll, I answered on behalf of my husband, who has been taking Acyclovir for about 6 weeks with great improvement. He started treatment with Acyclovir about 9 months after his first Meniere's attack. Brain fog (a constant issue) disappeared immediately, within the first day of treatment and has not returned since. He is no longer off balance and no longer suffers from nausea, dizziness, or hyperacusis. Prior to
Acyclovir, he was having weekly Meniere's attacks and used to lie down for long periods each day. In a nearly a whole year, he has not driven more than 5-10 miles from home. He no longer feels the need to rest for long periods and drove about 60 miles the other day with no problem whatsoever. He is sometimes hit with very brief feelings of discomfort that last seconds but do not persist...

I have been on JOH [diet] regime for over 3 years and it didn't help my Meniere's at all but I still take it because it has improved other areas of my health. I also went the Acyclovir for 3 months also with no change in my Meniere's...

Good Morning. I am really, really excited this morning as a LOT of my hearing is back! This is day 15 of acyclovir 800 mg x 3/da. I lost the fullness, brain fog, pains, itches, and hyperacusis after a week to ten days, but it has only been in the last 3 or 4 days that I have seen a slight and gradual improvement in hearing. Last evening, I felt that it had really started to come back more, and this morning it is a very significant difference. Yay! Now I am really looking forward to my audiogram next Wednesday. I have to admit that there were days that I was discouraged, and if it weren't for the encouragement of folks on here who told their stories of how you had to wait patiently for the results, I just might have given up a few days ago. So thanks to everyone. I am so happy we have this site! Antivirals should absolutely be the first line of treatment.

I'm very happy for you [REDACTED]! I am on day 10 without any improvement (yet). I don't know how anyone outside this forum could understand what getting a little hearing back feels like. For me, it's like coming home after a long time away.

Stay the course, [REDACTED]. For me, the return of hearing was really sudden. I think the main reason I am so happy to see some hearing return is that now I feel there is hope of not completely losing all my hearing.

[REDACTED] - keep at it. I think I noticed my hearing improving around day 12. And like [REDACTED], it was quite sudden - it was about 3 days from "hm...maybe that's slightly better" to "wow, I feel nearly 100% back!"

I started famvir on Aug 29th within 6 1/2 weeks my hearing (significant low-tone loss) was back to normal (!) as per audiogram and all symptoms gone! My process was very up and down. I stayed on 500 mgs (planned to take it for another few weeks). I have had a set back in which my hearing started going down just yesterday but it's not down much and I think it will pop back up. I may increase back up to 750 for a couple of days. I had cut out ginkgo and lysine- that may be why it went out again- so I won't do that anymore! I think I will probably stay on a maintenance dose for a long time. I have not taken SERC but had success with diuretics and also with prednisone. Anti-virals are much easier on the body than either of those! I think that ENT etc. must get on board with this treatment. NONE of my doctors including the Silverstein Institute in Sarasota knew anything about anti-virals for menieres.