

Families of Spinal Muscular Atrophy
 Transcript of Chat Live with an Expert
 Tuesday, April 17, 2005

Topic: Insurance

Our expert is Michael B. Horrow, Esq., a civil litigation attorney who represents consumers in disability, HMO and medical malpractice matters.

This transcript has been somewhat edited and revised to match questions with answers, to correct typos, and to remove extra remarks. Please note there may still be errors and omissions.

admin	Welcome to the Families of SMA chat room. If you have a question, you can go ahead now.
MH	Many of you have questions about how to access your health insurance to get the most fundamental needs for your child. One tip is to rely on your primary care provider. He or she should be equipped to start you with a list of what you need and what you can get from your health plan.
B	Good morning Michael, will you be covering the topics of US government assistance programs to SMA/MD affected individuals today?
MH	The work I focus on is with private insurance matters mostly but I am familiar with government issues and I can try to help. What is your question?
B	I have an SMA affected niece, and as she's growing up, there are various needs. The basic things like transfer equipment within the home, on the roads, personal assistance all cost a lot of money. Do you know any government programs that would help people in those terms? I also ran into agencies who stated that SMA is not one of the listed diseases that would qualify for assistance.
MH	Depending on which State she lives in, she can try to access the various programs at the State levels by looking on the State's website. Which agency said that SMA does not qualify for assistance?
B	This is a while ago. I don't remember the group's name. I was looking for assistive living type of help at the time. We live in California. Regarding the government website, do you have any specific programs you know of - either federal or state?
MH	In California, you can access the California Regional Centers.
B	Right – I've dealt with those guys before. I didn't get too far. I'll have to check on them again in case programs have changed or something new has come up. I'm not very hopeful but thanks for reminding me.
MH	Another tip to access your health care, therapy and medications: insist that your health plan identify the benefits available to you in writing.
R	My son has SMA and use a power wheelchair. Insurance companies place this item within durable medical equipment

	(DME) which usually has a low annual limit. The insurance companies are willing to pay the full amount for artificial limbs which start at \$15,000 and up but won't pay for powerchairs for people that rely on that for mobility. Is there any way to fight this?
MH	How did you obtain your health insurance? Employer? and if so, is the employer a government, church or school?
R	From my employer – a regular company, not government. It seems that most insurance companies consider all wheelchairs as durable medical equipment.
MH	The reason that I ask is that if your health insurance is through your employer, your health plan is subject to ERISA- a federal law that limits your remedies if you sue the health insurance company. Since your health plan is subject to ERISA, you need to review the definition section of the health plan or policy and if it is unclear, ask them to specify why the wheelchair is considered DME. I would suggest that if it is clear that a power wheelchair is DME, talking to a case manager with the health plan about using some of the resources to assist payment on the wheelchair.
R	My employer just switched insurance companies and I've been told they consider any wheelchair as durable medical because the item can be reused.
MH	If that is the case, your best bet is to suggest to the health plan that if there are other resources that you are not using, perhaps they would consider re-allocating some of the benefit to fund the wheelchair. Also, you could call the DME provider directly and suggest that they reduce the price to assist you.
R	Is there a way to somehow change laws that would make insurance companies not classify certain equipment as DME? I can't see the real difference between an artificial limb and a power chair for someone who can't walk. I would be willing to take up this cause but don't know how.
MH	Depending on where you live, I would suggest calling your State officials to try to encourage a re-classification of a wheelchair, and explain why.
R	Thank you!
J	Our 26 year old son was just diagnosed with Type III and is still employed. When he got the job (with a previous employer) in November, he was just beginning the diagnosis process and was taken back on the health insurance but told it would not cover a pre-existing condition. We have been afraid to utilize his health insurance and have gotten all support so far through NIH, where my husband is a long-term outpatient for a different problem. Do you have any suggestions of how to make sure his work health insurance cannot reject his claims?
MH	Since all health plan language is different, my suggestion for now is that you simply make the claims - if the claims are rejected, ask for it in writing and see if the pre-existing language applies to you.
J	Okay. I think we have been immobilized by fear of failure, but now that we finally have a diagnosis, we need to make a move.
MH	You have nothing to lose by sending in the claims. BUT, make

	sure you get a denial in writing. Do not accept an “over the phone” denial.
J	Is there any legal definition of “pre-existing”? My son had the same illness when he worked there previously, but we just didn’t know what was going on with his body.
MH	All pre-existing conditions are different. There is no one uniform definition - you need to look at the language.
B	In general, is van transfer equipment covered in HMO health plans?
MH	All HMO health plans are different and you must look to the language of the policy. Having said that, I have not seen such a provision that you could use to pay for Van transfer equipment but you could argue that the van transfer equipment is safety related which would prevent other more expensive injuries so in the long run, you are saving the health plan money.
B	Would you suggest calling member service to initiate the request or is there someone better to work with in the HMO organization?
MH	I counsel people who have members of the family with debilitating illnesses to encourage the participation of the health plan in their care - by that, I recommend getting the health plan to offer a “case manager” who can then advise on the benefits available and the needs of your family. Always though, get information in writing to avoid surprises when you rely on them.
R	Do you know of any circumstances where insurance would cover heating a pool or home renovations?
MH	No. I am aware of health plans that provide for aquatic therapy.
MH	Another tip: make a list of all of the needs that your family may face and then send a letter certified to your health plan and ask for guidance, in writing, as to what of these needs are available under the health plan.
B	As these SMA affected children grow and going to schools, the school has certain level of personal assistance (PA) provided for the special needs kids. Do you know of the same when the kids are in high school? college?
MH	I don’t. But I would suggest that in the area where your niece lives, a quick check of the surrounding high schools and colleges should be able to explain assistance that is available and may have scholarship or foundation money to help.
R	I live in Florida and my son is in high school with a full time aide that the school provided. I’m not sure what will happen for college though but I will be checking on that next year while he is in 10th grade.
B	Is this aid a shared resource for many kids or dedicated to your son?
R	Just for my son.
B	Wow. That’s good to know.
MH	Another tip: when appealing a denial of a insurance benefit, make sure you include all supporting medical records and medical opinions from doctors and health care providers - often, the health plans are not nearly as knowledgeable about SMA as you and your

	doctor. You must educate them about the illness and what you are trying to do.
R	Michael, last year before my employer switched insurance companies my son got a new powerchair. The insurance company did approve it but later backed out saying they would only cover it under the DME annual limit. Since this was never made clear I did pursue the matter which reached 3rd level appeals. The day before the appeal I faxed over 45 pages of information from doctors, websites, pictures, etc. Then 30 minutes before the appeal was scheduled the following day, they called me to say I had won the case! Sad thing is the misery that put my family through (2nd mortgage) when we thought they would'nt pay it. It pays to pursue it!!
MH	Great job. I love to hear that persistence pay off.
MH	Another tip: enroll your primary physician to suggest specialists and therapy options that will assist and improve your family member's illness.
admin	Our time is almost up. Michael, do you have any parting advice for us?
MH	Another tip: when you sign up or enroll in your health plan, keep your marketing documents and brochures - very often, the promises made at the sale or enrollment about your benefits differ from the actual benefits available. Use those materials to make clear what they promised!
admin	Michael, thank you so much for coming and sharing your knowledge with us today! Thanks for giving your time
MH	It was my privilege to help. Thank you for allowing me the chance to help. For those going, I will be at the SMA convention in Philadelphia in June.
J	Thank you for being here for us today! Good bye!