Our advice on protecting your personal medical data

We are writing to you jointly as Patient Advocacy Groups for our group of conditions, myotubular and centronuclear myopathy.

This week has seen a rise in the number of questions and queries about organisations looking for patient data. In particular, this was in relation to a new website that suddenly emerged in our community, called Rare Patient. Rare Patient is asking our families to volunteer our personal and sensitive medical data through social media, in order that they can connect us with researchers and new treatments as they become available.

To answer many of your questions about Rare Patient, they are owned and operated by a company called Seeker Health. Seeker Health is a private company that operates as a 'contact agency' to help find patients for clients that are working on drug development. Audentes Therapeutics have contracted with Rare Patient to assist with market research, and to provide an additional method of finding patients who may be interested in their drug development programs, including X-Linked Myotubular Myopathy, and to gather their personal patient information. We are not in a position to comment on that particular arrangement, but we do have some suggestions on what you might wish to consider when sharing your data with any company, institution or patient group.

Your information is valuable

As the field of research for our community gets more exciting, patient registries, databases, studies and trials are even more critical in the search for promising new treatments for rare neuromuscular diseases. The very rarity of these conditions make our participation and personal medical data invaluable for researchers, biotech companies and other companies involved in different ways in the search for effective therapies.

Multiple ways to participate in data collection

There are many rare disease registries that exist to gather such information, and they vary from patient-led and university/researcher managed to those owned and run by private companies. Their policies and approaches vary accordingly.

Our best advice to protect your personal and medical data

DO your research. If an organisation is looking for your data, make sure this is for a legitimate project which has been set up with all the necessary ethical approvals and data protections in place. If this information is not freely available on their website, ask for it.

DO look for the parent company or other sponsor of a website or advertisement. Who is providing the funding?

DO read all of the patient information provided by the organisation holding your data. There's a lot you might not expect to see in the small print.

DO check that small print. Who will have access to your data? What will they be using it for? Who will they be allowed to share it with? Will they sell it on?

DO think about the future. How long are they planning to keep your data for, and what are they going to do with it afterwards? Being a rare disease our knowledge and data could be useful to researchers for a very long time, way beyond what we can envisage now. If you are only going to register somewhere once, does the organisation you have chosen to hold your data this sound like the best place?

DON'T imagine that sharing your data is the only way for your child to get on a clinical trial. Biotech companies will not select any patient for a clinical trial. That would be unethical and is forbidden by law. Only the doctors in charge of the clinical trial will select patients

DON'T feel pressured. Just because our data is useful, and we desperately hope for a successful treatment, we should never feel obligated to share it before we are fully informed and confident that it's the right decision for our personal situation.

We hope you found this helpful and if you have any questions, do please continue to ask us.

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