Pairnomix

Finding others with a rare condition

If you (or a loved one) have been diagnosed with a rare genetic condition and undergone genetic sequencing, you may want to connect with other patients who have been similarly diagnosed. Individuals having your same gene mutation may share similar symptoms with you. They may also have the experience to understand and empathize with your situation.

Today's patient communities tend to take the form of a Facebook page or self-hosted website. A simple web search will help you find most websites, but here are some additional tips:

- Start by looking up your gene name on Wikipedia, which can link you to additional references and resources, including patient websites.
- Set Google Alerts for your gene name or gene abbreviation. This free service, offered by Google, will monitor the Internet for any mentions of your gene name across a variety of websites and then send you email notifications.

Whether you find and join an existing community or create your own, most patient websites contain the following items:

- A mini-biography of the patient hosting the site.
- Photos (if patients are comfortable posting them).
- Keywords that will draw researchers, physicians, and other patients, including:
  - Gene names, as well as their synonyms. The best search engine-optimized websites will have gene names in their page title, in main headlines, throughout each webpage, and as part of the domain name.
  - A list of all of the pathogenic or causative gene mutations identified in the patient's sequencing report.
- A description of the patient's symptoms that utilizes both medical terminology and everyday language.
- Details about the patient's condition from birth to diagnosis, including all attempted and current treatments, procedures and medications, and results.
- Contact information along with a dedicated support email and/or web contact form.

It's important to find a safe haven where you can engage with others who understand what you're going through. Patient websites are a great place to help you learn more about your condition, find the support you need, and share stories about your common journey.

Pairnomix empowers patients living with rare disease by performing personalized genetic research that enables physicians to make better-informed healthcare decisions. We're here to answer your questions about genetic research.

Contact us to learn more.

Adapted from an article originally written and published in Genome magazine by Pairnomix Board Member Matthew Might, PhD