



Phelan-McDermid Syndrome

INTERNATIONAL REGISTRY

FACTS ABOUT THE REGISTRY

- The PMSI registry is the largest database about people with PMS in the world.
- Registered 800 patients of known 1,300 foundation members worldwide.
- Most patient registries are for researchers alone, ours gives information back to the families.
- You don't need to complete all the surveys at once, as your info will be saved.
- All data collected is confidential, contact info held only by the Foundation.
- Provides de-identified data to qualified researchers.

WHY REGISTER?

- Empowers parents & families as you get access to information immediately.
- Connects families to research opportunities.
- Better characterises the syndrome, which improves diagnosis and clinical care.
- Information in the registry can be used to clarify needs of PMS individuals = support for your kids and family.
- Feedback to family incorporates world wide data from over 43 countries.
- Timely knowledge about clinical trials through the registry.

CHECK OUT THE REGISTRY AND SIGN UP TODAY!

<https://pmsiregistry.patientcrossroads.org>

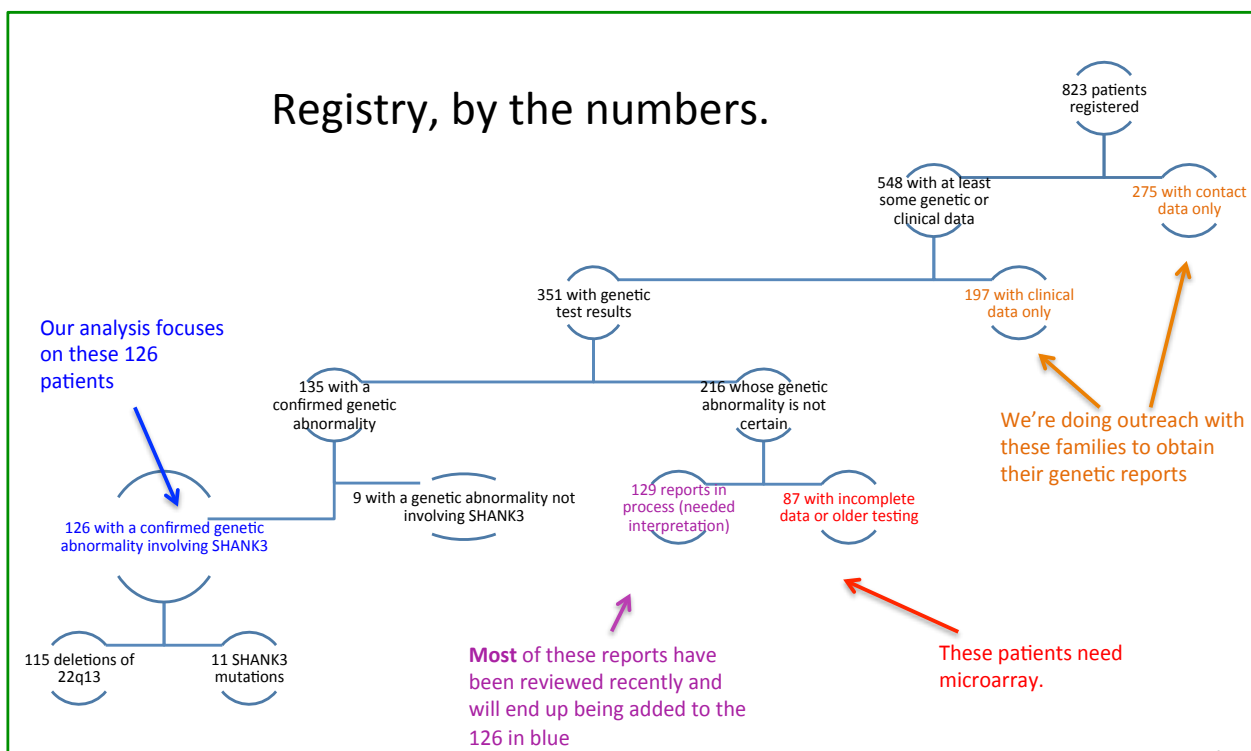
CONTACT US ANYTIME AT: PMSIR@PMSF.org



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A MESSAGE FROM THE REGISTRY TO YOU

- If you have registered please make sure you have "updated your consent options" (re-consented). This would apply to anyone that has not logged in since July 2014.
- Please **UPLOAD** your genetic report ASAP! **Most researchers are not looking at data for those who can't confirm their diagnosis with a genetic report.**
- If you have not updated your survey in over a year please go to "Red-Do" survey and update. We need longitudinal data. (If you go to individual questions and change their answer it will delete the original answer. By "re-do survey" it will keep the original answer and add the new one as the most recent.) This is important. We want to see what changes over time.



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