

CIRCULATING HOPE

A newsletter for people affected by GACI or ARHR2 due to ENPPI/ABCC6 Deficiencies

Meet the Board of Directors

The Board of Directors is comprised of members from across the globe who have come together out of dedication toward the same cause.

Vicki Dedeigbo is the mother of 7 children and lives in Australia. Vicki lost her first daughter due to complete organ failure caused by GACI in 2002. In 2005 she gave birth to a second daughter who received the same diagnosis and prognosis. However, her infant daughter responded to treatment and is now a vibrant and thriving 13 year old girl. Vicki is always happy to answer any questions. In addition to being a founding member of GACI Global and mother to 7 wonderful kids, Vicki has quite the menagerie including two dogs, a bird, a bearded dragon, and a blue tongue lizard.

Christine O'Brien lives outside of Boston, Massachusetts with her husband and their 3 children. Her oldest 2 children have GACI, with her son also having a second rare genetic disease called Loeys-Dietz Syndrome. When her children were first diagnosed, it was an incredibly scary time. There was very limited information available. This inspired her to seek out other families struggling with a GACI diagnosis. In addition to being a busy mother of 3 and a founding member of GACI Global, Christine works as a photographer and a swim instructor.

Liz Molloy lives in Dublin, Ireland with her husband and family. Their world was torn apart in 2005 when their 3rd child was born and quickly diagnosed with GACI. Despite treatment, he died at 4 months of age. 3 years later their newborn baby girl was also diagnosed with GACI and they were told to expect the same outcome. However, Liz's daughter is now a sweet, kind, caring 10 year old girl. Formerly a Sales & Marketing Manager in the Irish national telecommunications company, Liz now devotes all of her time to her family and is a proud founding member of GACI Global.

Anne Van Wyk lives near Dallas, Texas with her husband and their 4 children. Anne suffered the devastating losses of two sons due to GACI- first in 2001 and again in 2010. In 2013, Anne received prenatal bisphosphonate treatment after an amniocentesis indicated her unborn baby had GACI as well. The treatment stopped the calcification from progressing and after birth her daughter continued to receive treatment for GACI for one year. She is now almost 6 years old and is a spunky and outgoing little girl who loves life. Anne has had the opportunity to connect with other GACI families to encourage them and give them hope.

Jerry Van Wyk is also a founding member and is on the Board of Directors. When his first son passed away in 2001, the physicians suspected that he had GACI, but at the time very little was known about it and the doctors were not aware of any treatment options. In 2010, their second son with GACI received treatment, but also sadly passed away. Jerry is appreciative of the advancements of GACI research throughout the years. The small community of medical doctors, researchers, and GACI families have made great strides to understand this disorder and share a message of hope.



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L-R: Anne & Jerry Van Wyk, Vicki Dedeigbo, Saoirse Mulvey, Treasure Dedeigbo, Christine O'Brien, Michael Lemanski, Maren O'Brien Lemanski and Liz Molloy at the Global Genes Rare Disease Patient Advocacy Summit in 2018...

where the seeds of GACI Global took root!



Global Genes Rare Disease Patient Advocacy Summit

Every year Global Genes presents a Rare Disease Patient Advocacy Summit. This year the summit will take place in San Diego, California from September 19-20. If you are interested in attending this year's Rare Disease Patient Advocacy Summit, you can find more information at www.globalgenes.org. The Board of Directors will be attending and there will be a presentation on the latest research and development by Inozyme Pharma.

Please contact us if you have any questions about attending. We hope to see some of you there!

Tips for Parenting a Child with a Chronic Rare Disease

1. Learn as much as you can about the disorder.
2. Don't be afraid to ask questions.
3. Keep records. There can be a lot of information to remember!
4. Empower your child. Give them some control over the situation. For younger kids, this can be as simple as letting them choose if they want to take their medicine in a syringe or from a spoon.
5. Establish your "village." Set up a support network of family and friends around you and your child.
6. Ask for (and accept) help.
7. Find some time to take care of yourself. Date nights, gym memberships, tea and a good book... find a way to give yourself a small break.
8. Engage with support groups.
9. Network worldwide. This is where the internet is a wonderful tool! You may be the only family in your area dealing with this diagnosis, but you can still connect with families across the globe who are facing similar battles.
10. Educate Others. Nobody knows your child better than you. And parents of children with rare diseases often become experts on that disease. Share your knowledge, share your journey.

Please refer to www.gaciglobal.org for more in depth strategies for parenting a child with GACI.



GACI Global
circulating hope

MISSION OF GACI GLOBAL

GACI Global is a nonprofit organization whose mission is to connect families affected by Generalized Arterial Calcification of Infancy or Hypophosphatemic Rickets caused by ENPP1 or ABCC6 Deficiencies to each other and to the medical community. The organization strives to provide current educational resources and supports ongoing research. GACI Global is...Circulating Hope