SHARON LAGAS MY TURN

'Do something' turns grief into solid progress

Have you heard of a rare genetic disease called Alport syndrome? I hadn't either until 2004.

In the span of one month, I lost my 38-year-old brother to the disease, discovered that my brother's two daughters had inherited it, as had my mother, myself and two of my three children. Six family members diagnosed at once with the same rare disease — how do you handle that?!

This disease causes kidney failure, hearing loss and vision problems and devastates families in a never-ending cycle, generation after generation.

After discovering this, I did what any mom would do — I began researching the disease and reaching out to others to connect, find resources and support.

A dearth of information

As you might imagine, there was nothing available except overwhelming medical articles on the Internet telling me how my boys would lose their kidney function by age 25, preceded by hearing loss.

I was reliving the nightmare of challenges I watched my younger brother go through — kidney failure at 16 years old, dialysis during his high school years, two transplants and a multitude of side effects due to immunosuppressant drugs, including hip replacement and early death. It was a very depressing and isolating time.

I decided that I could not be a passive participant in this cycle and that I had to do *something*.

It took two years, luck and good timing to meet someone who wanted to help me. This wonderful mom was not affected by the disease but was compelled by our story, as she had sons the same age.

So, on the side of a soccer field while watching our boys play, we conceived the Alport Syndrome Foundation. We connected with two other families with Alport syndrome and began to put all the pieces in place.

The foundation received its official non-profit status in 2007 and shortly after launching the website, we were immediately contacted by patients from all over the world reaching out for information, resources and support.

We have connected almost 10,000 stakeholders (patients, family members, clinicians, researchers, donors) in 75 countries since we began 10 years ago and helped other patient groups get started in other countries.

Developing this foundation, and working tirelessly with other patients and families and volunteers, as well as our Medical Advisory Committee, has allowed us to give a voice to the Alport syndrome community, form a support network, advance research, support a patient registry, sponsor patient and academic meetings and collaborate internationally.

All our efforts have brought us closer to our dream of finding new treatments to prevent kidney failure by creating a community that encourages researchers, biotech and pharmaceutical companies to invest in Alport syndrome.

There are currently two clinical trials that have begun on potential treatment therapies. This is very different from 10 years ago.

Help from Arizonans

We could not have accomplished any of this without the continuing support of our donors — many from our community here in Arizona.

They have been on this journey with us and have helped raise awareness and funds for the past 10 years since our first 5K for Healthy Kidneys in 2007.

We have had over 3,000 participants and raised over $400,000 at this event. This year's 5K run/walk for Healthy Kidneys will be on April 2 at Kiwanis Park in Tempe.

My family and I are very thankful for this community that we have built together. It has allowed us to heal — we have become proactive instead of feeling like victims.

Doing *something* when you are most vulnerable gives you hope. Translating that hope in action equals empowerment, which in turn leads to progress to making a real difference.

Details: alportsyndrome.org/donate/fundraising-events/5k-healthy-kidneys/.

Sharon Lagas of Phoenix worked in environmental consulting before co-founding the Alport Syndrome Foundation, where she serves as board president.