



The inaugural ALAB members at the CRN Family Conference in Philadelphia, July 2019.

The Healing Power of Pets

When deciding to pick an article for this issue of the newsletter, we chose pets. According to an article from Harvard Health Publishing, “Owning a dog can prompt you to be more physically active.” They help us through our rare disease and the tough times we face. From the snuggles they give to those cute faces that put a smile on our faces, they also make great companions reducing feelings of isolation and loneliness.

A Boy and His Dog By Steve Schleuder



For many dogs it seems like a natural instinct, like they were created to be natural healers with their presence. Growing up from the ages of 10 to 23, I had a beautiful and loving Golden Retriever named Coby. Coby was with me through physical, emotional, mental, and spiritual illness caused by direct or indirect symptoms of cystinosis. When I got my kidney transplant at age 11 and I was resting in my house recovering, he would constantly lay by the couch with me. Whenever I felt tired down into my soul, he would lick my hand or put his head under my hand for me to pet him. Sometimes clichés are true; dogs are a man’s best friend.



My Dog Skylar By Jana Healy

When I think of my dog Skylar, the first thing that comes to mind is his love and loyalty and how he definitely give lots of snuggles. He makes me smile and keeps me active.

Pancho

By Karen Gledhill



This is Pancho, named after a John Prine song. He is one of two of cats we currently own. Pets have always been an important part of my life. When I was first married, my husband bought me a St. Bernard, "Jackson Wolfgang". He was there when I was told I had a failing kidney and needed dialysis, and ultimately, when I found out I had cystinosis.

He was my best buddy and I would tell him my updates on our walks. I know he understood. He gave me unconditional love no matter my mood (and there were many BAD MOODS). He was with me during my roughest patch including dialysis, work up, and my first transplant 40 years ago (WOOHOO!)

Now I have Pancho, who makes me laugh. Who knew cats were klutzes? Although, I am not really a cat person, he has changed my mind. As you can see, he is sitting on the papers that I was working with! Try to ignore him...never! Petting him keeps me calm and calm is good for all we are going through these days!

Life with Fiora

By Cheryl Simoens



Having a rare disease does sometimes present issues in one's life. Now we have also thrown a pandemic into the mix and I'm beginning a Master's program this fall, however, I am very lucky because I have my dog Fiora by my side. When I feel isolated, stressed out, or just sad, I curl up with her on the floor or on the couch. She provides me with the ability to feel supported and brings me joy and comfort. I have explored many many parks, trails, and outdoor areas that I wouldn't have if I didn't have a dog I needed to walk. Fiora brings happiness into my life and allows me to care for someone other than myself; this is a tremendous gift.

About Lola

By Christina Morris



About five years ago, I adopted my dog Lola from a shelter. Ever since that day my life has improved. It's a crazy story how I found her. One day I was watching the news (which is rare) and her picture popped up on the screen and I got this unexplainable feeling. The news story was about her needing a forever home. I just knew that it had to be me that adopted her. Lola is deaf so I thought that we could relate due to our disabilities. Ever since then I believe both of our lives have improved. She is eight now and I am so glad I saw her that day on the news.



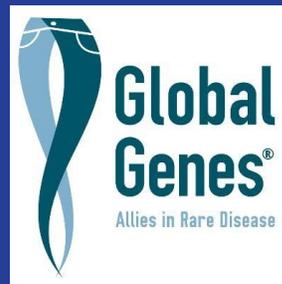
Fall 2021

Sara and Angel By Sara Healy

Having a rare disease can be trying at times and its nice to have a pet by your side. My dog, Angel, has helped me so much in my life. I consider Angel to be my emotional support dog. Some days I can get pretty emotional, and this disease can be mentally trying but having Angel has helped me out so much. There is just something about her presence; the wagging of her tail, the cuddles, and her playfulness. She cheers me right up and makes me feel at peace with myself and my situation.

Rare Disease Day Events - 2022

Rare Disease Day is February 28, 2022. It is a time to raise awareness about cystinosis, rare disease in general and the impact it has on our lives. Here are some events you may be interested in.



- **Capitol Hill Rare Disease Week:** February 28th - March 2 will feature Rare Disease congressional caucus briefings, a documentary screening, legislative conference, rare artist gallery opening, and more at everylifefoundation.org.
- **“Show Your Stripes”** by visiting NORD’s website: rarediseases.org/rare-disease-day. They ask for your help lighting up as many buildings and landmarks as possible for Rare Disease Day.
- **Global Genes “Care About Rare”** campaign is available at globalgenes.org.

About ALAB

Founded in 2019, ALAB stands for Adult Leadership Advisory Board. Made up of adults living with cystinosis, ALAB aims to educate, inform and inspire our community. ALAB is supported and largely funded by the Cystinosis Research Network.

Current members: Chairperson Jana Healy, Vice Chairperson Steve Schleuder, Secretary Christina Morris, Briana Kaye Dundon, Brian Ensor, Karen Gledhill, Sara Healy, and Gracie Smith.

