

Board Member Spotlight | Q&A with Tony Ferrandino

Tony lives in Newtown, PA with his wife Katie and son Gavin. His son Drew passed away in 2014 from CLN2.



When did you discover BDSRA?

2007 — shortly after my son Drew was diagnosed. My first conference was in Rochester.

Who is the person who brought you into the BDSRA Community?

Lance Johnston — Like many newly diagnosed parents, I found the BDSRA on the internet and called — literally from the hospital when Drew was first diagnosed.

Who inspired you to join the BDSRA Board?

Tracy VanHoutan

What has kept you connected to the BDSRA Community?

For a short time after my son Drew passed, I felt the emotion of wanting to forget about Batten disease. After a short time, you come to grips that Batten Disease is part of you and trying to forget just never happens.

What gifts do you bring to the board?

My talents are more in the area of finance and with the help of our family foundation Drew's Hope, we co-fund research projects with the BDSRA and other family foundations. One of my future goals is to bring family foundations together to continue the initiative that Bob Jensen started.

When did you join the board?

2012

Where was your favorite Board meeting?

El Paso, Texas — The days were filled with meetings. I found the evening very fun in El Paso. I purchased cowboy boots on that trip.

Why did you want to join the BDSRA Board?

To try and leave the organization better than when I came and push the science along while continuing the much-needed support programs.

Why should others consider becoming board members?

The organization is small enough that one person with drive and determination can make a difference. One can help mold the organization to what you want it to be. And some of the greatest people I have met in my life are fellow board members.