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Holiday Reflections



From Our Family to Yours

*Happy Holidays! May you and your loved ones
enjoy a wonderful, blessed and
happy holiday season!*

2012 has been an exciting year at ASF. We've seen the results of outstanding research and the hope of potential treatments yet to come! The addition of our full-time resource specialist has been a tremendous asset to all of the families that have been helped over the past eight months. We've enjoyed another successful walk with the largest number of attendees this past May. As Executive Director of ASF a few things that I am most proud are 1) the establishment of the two new Angelman Syndrome comprehensive clinics at the University of North Carolina and Massachusetts General Hospital; 2) the online interactive behavioral modules and 3) the recently released Angelman syndrome diagnostic awareness video. All will have a direct positive impact in helping families of people with Angelman syndrome, from diagnosis throughout their lives with AS. As we continue to make tremendous progress in our research efforts toward treatment and a cure I am ever-mindful that the ASF is equally tasked with helping families in the here-and-now deal with AS every single day--and will always keep our families as the priority as we continue with the programs and services that will have the greatest impact and outcomes.

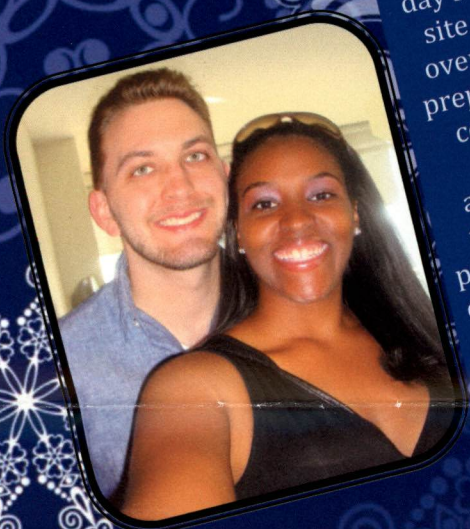
As Executive Director I oversee all aspects of the operations of the Foundation, programmatically, administratively and in our fundraising efforts. I have the privilege of working directly with researchers, managing the ASF-funded research grants, participating in NIH and RDCRN meetings, working with the experts on the behavioral panel, working directly with clinicians at health-care institutions to establish clinics across the country; I am privileged to speak on behalf of, and represent, the ASF at various events, meetings and presentations. I sit and work on various committees (including the Finance and Executive Committees) as well as attend ASF Board of Directors meetings. I'm responsible for securing and administering all ASF contracts and agreements in conjunction with the Board. Additionally I am responsible for all human relations (personnel) management, and day-to-day operations. I work with the public relations team to develop various public relations strategies for on-going awareness and promotion of events and ASF's good work. I also have an integral role in donor development, cultivation and stewardship.

For the Braun family, 2012 has and continues to be a year of transitions. We sent Joe off to college this fall to Bowling Green State University in Bowling Green, Ohio. Jonathan turned 16 and started driving this fall (which, with a hectic family, school and sports schedule, has actually been quite helpful!) Kimberly continues to do well in school and continues with her competitive gymnastics. The biggest transition is yet to come as Kaitlin will turn 22 this December and that is when the "bus stops coming". We have been working toward this day for the past 21 years and the past few years in transition has helped us to develop a schedule at school that now looks very much like what her days will look like once she exits the transition program. Our hope and dream for Kaitlin is that she will continue to grow and gain additional skills even as she no longer attends school but becomes even more fully integrated as a young woman into the community. With four teenagers in our home there is hardly a quiet or dull moment, as you might guess, and Tom and my schedules revolve heavily around their schedules and events when we are not working. We were, however, very blessed to celebrate our 27th anniversary this summer and look forward to many more in the future!

As we look toward the New Year, may you and your family reflect on the many blessings that have been given to you. May you find joy in the things that have past and hope for the wonderful things that are yet to come!

Happy Holidays!

Eileen



My name is Kevin Wick, I am the Web Manager/Communication Specialist for ASF. As we approach the holiday season, I am most proud of the launch of our new website earlier this year. The transition seemingly happened overnight, but in actuality took many months of advanced preparation, research, and development to execute. Careful consideration was taken to ensure the new site met the needs of our community and provided as much tools and information as possible. Thank you to everyone who provided feedback, it is truly invaluable and will only improve your online experience going into the new year. I wish everyone in the AS community a happy holiday season filled with love, happiness, and—of course—laughter! As for me, I'm spending the holidays with my wife and our families. I'm looking forward to eating great food and focusing on the little things that make this time of year so special.

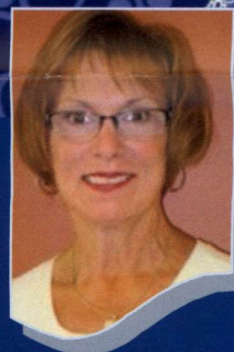


Lisa Lueders - Accounting Manager / Office Manager

My professional hopes is that we as a team are able to make more progress by increasing the raising of funds to provide additional resources to assist our families. I feel particularly proud of the completion of the Annual Financial Audit

I am very thankful for my family and friends; especially to have my children who are the world to me. Every year my siblings and family get together to share the holiday spirit through celebration and gift giving.

Donna Schalke – Development Assistant



I have one of the most gratifying assignments! I am personally reaching out to donors to extend our thanks and gratitude for their support of the Angelman Syndrome Foundation, helping us to make our mission possible. We look to the future with great optimism that we will reach our ultimate goal – positive treatment & hopefully a cure. One of the organization's many highlights of 2012, was the opening of the second comprehensive AS Clinic at Massachusetts General Hospital in Boston that emphasizes the unique challenges of caring for adults with AS.

I have so much to be grateful for this past year, my family, our health, and so much to look forward to, with the birth of our first grand-child an anticipated highlight for 2013! Each Christmas morning we traditionally play "hide the pickle". Although the children are all adults now, it is comical to see the sibling rivalry come out between them for those few minutes – who will be the first to find the pickle and claim the extra present!

Karen Craig, Administrative Assistant,

This year has brought great change to the ASF. I am particularly proud of working on setting up and administering the new database. Currently, I am working on our new system to import data from the website to the database. This has been a great undertaking and hopefully when completed should be a major improvement.

One of my favorite Christmas Eve memories was a year that it was very cold out and we had Christmas Eve service in my home. My mother-in-law played the piano, told the Christmas story and we sang Christmas carols. Each of the children were able to place a nativity figure in the crèche at the appropriate time. It was one of the most enjoyable Christmas services that I have been too.

My wish for the ASF community is for the research that ASF funds, to find a way for AS individuals to live a more productive and normal life that is within their capabilities.



Sheila Wenger -

When I was a kid, my favorite thing about the holidays was the presents! Every year the family would draw out present opening time by having to do our holiday tradition of joining hands and singing Christmas carols around the Christmas tree. We would always have to try to sing a Norwegian song that no one could remember the words to and then finally - presents! As an adult, my favorite thing about the holidays is, well, just about everything. I love the decorating, the parties, baking, shopping, Christmas music, Christmas cards, Christmas movies, wrapping presents, crazy family traditions, opening presents and spending time with family and friends. I

even enjoy that my husband competes with our neighbors to "Griswold" out our house.

As the year ends, I wish to thank you for the opportunity to serve you. I have worked for ASF since 2003 and am currently the Special Events Coordinator and Meeting Planner.

My position allows me the opportunity to work with many wonderful volunteers and families to run successful fundraising and awareness walks and events as well as the biennial conferences and scientific symposia.

As we look to the future, I look forward to a new year with tremendous strides and breakthroughs in research and therapeutic discoveries. I also look forward to the opening of additional AS clinics across the nation as well as an eventual cure of AS. I wish you and your family a wonderful Holiday Season and a fabulous New Year!



Anna Hanson

I am the Prospect Researcher at ASF. I have been working to identify potential new donors including individuals, foundations, and corporations. I am busy doing research and analysis, and putting together comprehensive profiles to prepare us for developing these new relationships and partnerships. I enjoy serving the ASF community because I want to raise money and awareness about the disorder. I want very much to see individuals with AS, and their families, receive the attention and support that they need. And I know I can help our families best by serving the foundation administratively.

I am a Midwest girl - born and raised in Minnesota but have lived in IL for over ten years. I maintain close connections with my family and friends in both states, as well as with those I have around the world. I have an adventurous spirit and love to meet new people and see new places. But the holidays always take me home to MN where my family celebrates our German-Alsatian and Norwegian heritage with traditional foods, drinks, church, good conversation, and A LOT of snow sports. Christmas time always includes, skiing, skating, sledding, ice fishing, and sometimes snowmobiling.

A Christmas without snow is definitely not Christmas for Minnesotans!

Season's Greetings,!

My name is De'itra Rucker and I am the Family Support Manager and Resource Specialists. Those are just fancy titles that mean I'm the person families turn to at their various points of needs as they walk this AS Journey. Since joining the AS team in April of this year, I have worked very hard to continue developing and expanding the breadth and depth of support we provide to families as well as providing educational resources and awareness opportunities community wide and beyond. I am most proud, that in that time, we've personally welcomed and supported over 150 newly diagnosed families. There is much work that remains, but I couldn't be prouder of the ground we've covered this year.

Personally, I love the holidays and really enjoy the time to spend with family and loved ones. Taking time to dote on all the new babies and my own 12 year old, who will always be my baby (much to his chagrin)! I have a large family and it's not uncommon for forty or fifty of us to gather and celebrate our faith and love together during the holidays. Every year we get up at midnight, just after Santa's taken his leave and exchange gifts. Then we're off early to sunrise services at church, celebrating our faith tradition and giving thanks for all that we count as blessings. Finally no Christmas would be complete without a hearty feast, replete with all our famous family recipes and dishes, passed down through the years.

This always proves to be a joyous season of reflection, thanksgiving and renewed hope for the seasons to come... and this is my wish for the entire AS community!

From our Family to Yours... Seasons Greetings!

