

# The Even Exchange

*Meeting your goals for good health*

Vol. 15, No. 1

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## *From Mary's Desk*

**Never doubt that a small group of thoughtful and committed people can change the world. Indeed, it's the only thing that ever has. - Margaret Mead (1901-1978)**

Over the past year KS&A has made tremendous strides in targeting new resources to help us build our capacity to identify and meet the needs of those with X and Y chromosome variations and their families and health professionals. Certainly at the top of the list are the many volunteers that serve as KS&A staff and help out at our many events and activities. Our volunteers donate their time, energy and creativity without any compensation and only with our warmest and most sincere appreciation.

Even as we grow into the next developmental stage of our organization, our success will continue to depend as much on the solvency of this critical core of dedicated and active volunteer members as on our ability to attract significant and secure funding. Our volunteers run our programs, manage our website, plan our conferences and retreats, write for the newsletter and website, write grants and development plans, answer inquiries about X and Y chromosome variations across the lifespan and everything else that we need to do to build our capacity to meet the needs of the X and Y chromosome community.

We want to acknowledge everyone who has lent a helping hand to KS&A this past year for their time and support. And we want to invite you, encourage and inspire you – if you are not already a volunteer – to join our ranks. Just give Kathi Henry, KS&A Executive Assistant, a call at (888) 999-9428, ext. 21 or send her an email at [khenry@genetic.org](mailto:khenry@genetic.org).

Mary Davidson, Executive Director

## 2005 Adult Retreat Weekend

Lloyd Tuckman, Adult Retreat Participant

One night I received a phone call from a KS&A representative. This individual asked me if I wished to come to a weekend for adult KSers. After agreeing to go and going, I drew a *web* to remember what we did, and how I felt. Then, on the bus ride home to the airport, we were all sitting and discussing the weekend. And with everyone's help, we spun out further the *web* that was already taking shape in my own head. This group *webbing* effort

helped me to come up with this article about the Adult Retreat.

In the next KS&A newsletter, I'll share more about the *webbing* technique. Like most KSers, my thoughts come fast and without any hierarchical order. *Webbing* allows me to jot my thoughts down, as they come to me, and then go back later and organize them into a written story or report or presentation.

*continued on page 5 (Adult Retreat)*

## Update on the Triple X Arm of KS&A's Sex Chromosome Coalition

Jill Balfour, Triple X Program Coordinator

It has been about one year since I accepted the offer to join KS&A as a Program Coordinator for the Triple X arm of our sex chromosome coalition. I am happy to report it has been an interesting and busy year. The highlight of the year was attending my first conference, held in Kansas City in July 2004. What is most noteworthy is that we had six families in attendance representing the Triple X community. I know I'm not alone in saying this was truly a worthwhile experience for us and that this experience helped us feel very much part of the larger sex chromosome variation (SCV) community.

Many of the issues we confront with Triple X (47,XXX) girls are also present in XXY and XYY boys. Triple X girls are often described as having hypotonia as infants; speech and motor delays; potty training struggles; sweet sensitive temperaments; shy approaches to people and situations; noise sensitivity; fears and anxieties in school; clumsiness; struggles with reading and math; ineffective reactions to bullying. The similarities among X and Y chromosome variations and between Triple X, XXY and XYY are often greater than the differences! I know the Triple X parents continually struggle

*continued on page 8 (XXX Report)*

## Advocating for Your Child: You Are Your Child's Best Advocate

Leslie Petruk, Mom to Brandon, 3 yrs old, XYY; XYY Program Coordinator

I knew that going into the whole school IEP (Individualized Education Plan) process and dealing with my particular school district was going to present a significant challenge. I had spoken with many parents of children with sex chromosome variations as well as our local Exceptional Children's Assistance Center

*continued on page 10 (XYY Advocating)*

# Chairman's Message

Dear KS&A Members and Families,

This past year has brought me into contact with a great number of individuals who are personally affected by X and Y chromosomal variations, and your families, medical professionals and loved ones. At the Pediatric and Adolescent Conference last July, as well as at the Adult Retreat that we held just a short time ago, I was able to visit with many of you about your lives, your hopes and the many goals we share in common. I am truly awed and inspired by you, and encouraged by your passion to continue our work to build an organization that will materially improve all of our lives.

KS&A is a member-supported organization that relies on your tax-exempt donations for its financial sustenance, and on a 100% volunteer staff for carrying out programs and operating responsibilities. Accordingly, we want to publicly acknowledge the generous gifts that have made it possible for us to work for this worthy cause. Besides the financial contributors who have expressly consented to their names being listed (see page 7), there are numerous other donors who are equally committed to KS&A but prefer to remain anonymous. To all of these individuals, as well as our numerous volunteer staff who give tirelessly of their time, we are extremely grateful. Thank you.

I would also like to acknowledge the men who attended KS&A's recent Adult Retreat, where Mary Davidson and I had the pleasure of getting to know many of you much better. We thank all of you for your candor, your honest story telling and your supportive words and deeds. Many of you have remarked that this event was a great inaugural effort, and have complemented the innovative format. On this basis, we are now in the process of planning another such event "by and for" adults with the condition, where we can build on what we learned this time, and make it even more productive.

As many of you know, one of the foremost reasons for having a national organization is to be in a position to encourage and promote research efforts into new treatments and improved therapies that are specifically focused on our members' needs. I am pleased to relate that we are making progress in these areas, about which I look forward to providing details in an upcoming newsletter and/or targeted appeal.

Please continue to work with us to make a much-needed difference in the lives and community of those with X and Y chromosome variations.

If you can afford to do so (or have contact with someone who does), please assist us with a tax-exempt contribution, or by recommending KS&A to friends, family members, colleagues, businesses and foundations that you know take an interest in bequests to worthwhile non-profit causes. In addition, we are always on the lookout for additional volunteers. If you have a few hours that you would care to give toward this effort, please call and let us know your specific interests.

Please call or write me at any time. I welcome your questions, comments and suggestions.

Warmest regards,

Robert H. Shelton, Executive Chairman

[RShelton@genetic.org](mailto:RShelton@genetic.org); (888) 999-9428, Ext. 22; (949) 858-8384

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### Please update your KS&A records today

- Fill out the form online at [www.genetic.org/ks/member\\_info](http://www.genetic.org/ks/member_info);
- Call us at (888) 999-9428 and speak with Kathi Henry ([khenry@genetic.org](mailto:khenry@genetic.org)); or
- Submit a newsletter article/ subscription/change of address (see back page).

## The Even Exchange

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## KS&A Listservs

### *Serving the X and Y Chromosome Communities*

Email is a powerful communications tool. Through the “magic” of email we are instantly brought together, no matter the location, into virtual contact with each other and united by a common theme. Email lists are convenient, fast, and remove the barriers of time and place to connect us to other persons with a similar concern. KS&A’s lists are really an *intentional virtual community*, intentional because we have a purpose, virtual because it isn’t a physical reality and community because we are a group of people joined together by a condition. We can communicate with other members of the XXY, XYY and XXX communities to talk about common issues, differences and to exchange ideas, resources and solutions. Our lists are hosted on the Genetic Alliance’s private server, so there will be no advertising associated with them, and our confidentiality/privacy is respected.

The discussion support lists have been created for you to exchange any ideas, information, news, comments, gripes, fears, or whatever, related to X and Y chromosome variations. It’s a place to deal with issues, to give and receive support, and to build your knowledge about the various syndromes and issues and how to live better, fuller lives with them.

KS&A has eight lists organized around developmental age and/or sex chromosome aneuploidy or variation (SCA).

- **PedsUnder3** - Issues of parents of children 3 and under with an X or Y chromosome variation
- **Peds4-7** - Issues of parents of children 4 to 7 with an X or Y chromosome variation
- **XXY Peds8-11** - Issues of parents of sons 8 to 11 with 47,XXY
- **XXY Adolescent** - Issues of parents of adolescents and dependent young adult males with 47,XXY
- **XXY Adult** - Issues of young adults and adults with 47,XXY
- **3X** - Issues of families and individuals dealing with females who are Triple X or 47,XXX
- **2Y** - Issues of families and individuals dealing with males who are 47,XYY
- **SCA\_seizures** - Issues of families and individuals who have seizures and an X or Y chromosome variation

We recently decided to expand the PedsUnder3 and Peds4-7 lists to include issues of parents of 47,XXX and 47,XYY (in addition to 47,XXY) because we knew that the X and Y chromosome variations share so much in common, especially during the early years. This way, we can truly benefit by sharing what we have in common and taking the more condition-specific concerns to the lists that are set up for that purpose.

There is nothing richer than common exchange and we all look forward to seeing what this new re-organization brings of value to all of us!

Sherryl Belinsky, KS&A Web and List Manager

## 2004 Pediatric/Adolescent Conference

### *We Strengthen and Uplift One Another!*

First of all, I want to thank all our speakers, volunteers, and participants who attended the Kansas City conference. Without you, a conference simply would not be possible.

Our conference started Friday, July 16 with a Pediatric Clinic run by Mary Yeiser. Parents had valuable one-on-one time with Dr. Alan Rogol, pediatric endocrinologist, and Carole Samango-Sprouse, Ed.D., neurodevelopmentalist. Winnie Dunn, Ph.D. was our first speaker - a leading voice regarding *Sensory Integration*. And that evening we enjoyed a KC Royals baseball game and, to top it off, they actually won!



Here are just three of our many conference speakers and long-time KS&A supporters. Left to right, Jay Giedd, MD; Carole Samango-Sprouse, EdD; and Liv Clasen, PhD.

Saturday was a day packed full of information and speakers. We were honored to have Dr. Rogol speak on *The Impact of Androgen Therapy*. Dr. Scott Page presented *Meiosis and Chromosome Inheritance*. We were then challenged by *The Disclosure Dilemma*, an insightful presentation by Mary Yeiser, RN, BSN and mother of a KS child. Long time favorite, Dr. Jay Giedd, followed with *Brain Imaging Research*. Lunch was then served while a silent auction helped offset conference costs. I want to give special thanks to Tim Clark, who donated many of our auction items. Stephanie Sackovich, LCSW, then took us into the world of *Family Dynamics and Relationships*. Next up was our own Stefan Schwarz with a touching *Perspectives from a SCA Adult with a SCA Child*. Next our superb new Executive Director, Mary Davidson talked about *KS&A's New Vision and Directions*. The day wrapped up with everyone’s favorite activity, *Support Group Meetings!* I know, I know, you wanted more time!

Sunday started with a wonderful presentation by Carole Samango-Sprouse, Ed.D. about *Developmental Pediatrics, Ages Birth to Five*. A first time speaker for KS&A was Stacy K. Betz, MS, teaching us about *Language and Cognitive Connections*. Carole Samango-Sprouse, Ed.D. then gave a second presentation about *Developmental Pediatrics, Ages Five*

*continued on page 6 (Ped/Adolescent Conference)*

## **Lennie Wilson, Director of Scientific Communications Services**



**Lennie L. Wilson, RN, CS**

*It will take many minds, working with a single focus in a partnership for wellness, if we are to remove obstacles to care and treatment of SCAs.*

When you or your child was diagnosed with a sex chromosome aneuploidy (SCA), you may have searched the Internet, visited a medical library or reached out to a trusted health care professional among your friends. You may have asked this friend to explain SCA or to unlock the door to health and medical research available only to professionals. In late November 1999, a dear friend called to ask my help in finding information and treatment strategies for his unborn son with a prenatal diagnosis of XXY. He wanted to understand what he, his wife and family might expect. I happily accepted the challenge.

Perhaps my friend chose me because he remembered my involvement with a high-profile media case about a genetic disorder called osteogenesis imperfecta. I had been serving as Chief Nurse for the Illinois Department of Child and Family Services and as a consultant on medical neglect or child death cases. In that case, a child died of the consequences of his genetic illness while in the home of a non-relative caregiver. Misinformation about osteogenesis imperfecta led to criminal charges against the caregiver and her children being removed from their home. I recommended that the caregiver's children be returned and told the court how a glaring lack of osteogenesis imperfecta knowledge drove wrong decisions. Opposing lawyers said I was "just a nurse," implying I couldn't know. Yes, I was "just a nurse," a nurse who knew that a microscopic view, lack of information or misinformation will lead to poor decision-making. After a two-year absence, the children were returned to their parents. Both the mother and I cried when it was final.

An advanced practice nurse specializing in child and adolescent mental health, I have worked in the field of psychiatry for 27 years. I became an RN in 1977 after graduating from Lewis University in Lockport, IL, with a Bachelors of Science in Nursing (BSN) and earned a Masters of Science in Nursing (MSN) in 1981 from Lehman College at the City University of New York. My master's thesis tested six variables on 243 adolescents. I also attended the Family Institute of Westchester from 1983 to 1986 and am a trained family therapist. Nursing, like medicine, has specialties and certification boards. I am a Clinical Nurse Specialist, certified by the American Nurses Association in 1985.

When my friend first asked my help, I cried. I knew the obstacles and ongoing challenges he and his family faced. But I underestimated his love, devotion and determination for his son. Nothing would stand in his way to get the very best for his son. Since then, I have discovered he is not unique; hundreds of other parents like him are members of KS&A—devoted and determined to help their child, no matter the obstacle. They have inspired me.

My friend and I visited all the medical libraries in NYC, copying articles on KS and following the endocrine literature for treatment strategies. Our findings were extremely limited, but our combined hope and faith kept us going.

My inquiries to colleagues brought discouraging replies: they only knew what was written in medical texts and what they had learned in medical or nursing school. Reaching out to pediatric specialists at the top nursing schools to find the KS expert, I found paternalistic attitudes and a limited view of what could be accomplished. I was basically told nothing needed to be done until the child was a teenager and, even then, nothing would change the course of the disorder.

While I reviewed articles and tracked referenced authors to find the thread conducive to healing, the parent searched the Internet for self-help groups and found KS&A, Melissa Aylstock and Carol Samango-Sprouse, Ed.D.

It was now January—two months later—and a baby boy was about to be born. By this time, I was finding loads of information and reading everything I could find. I finally got to meet the baby. He was beautiful! He had a sweet angelic face, a gentle disposition, ten fingers and toes, and lots of hair. His father told me we still had to meet all of the baby's needs, so I continued the search.

Soon, my extensive findings, including research and articles from many different perspectives and disciplines, demanded cataloguing. With my sister Rammie's help as an MIS

*The "Director of Scientific Communications Services" is responsible for gathering and indexing scientific information pertaining to X and Y chromosome variations and related health and wellness issues from key scientific journals and medical publications. The individual filling this position will periodically disseminate information from these publications in the format best suited to KS&A's various constituencies, including program coordinators and other staff, members, medical professionals, educators and research scientists. As time permits, he or she will provide support for these individuals on project-specific assignments where such services are relevant and/or required. KS&A is thankful and honored that Lennie Wilson, RN, CS, has agreed to accept this position on a volunteer basis.*

*continued on page 9 (Lennie Wilson, RN)*

## The 2005 Adult Retreat was a Success Thanks to:

**Herman and Associates**, and to Ken Herman, PhD; Patricia Sullivan, MA; Ed Oleksy, PhD, for contributing your time and energy as co-facilitators of the Adult Retreat and for your past and future involvement in KS&A!

**Solvay Pharmaceuticals**, for continuing their many years of financial and program support for KS&A through a generous donation to help us offset Retreat costs. We look forward to identifying future opportunities for collaboration!

*continued from page 1 (Adult Retreat)*

More about this *webbing* technique in the next newsletter; but, for now, back to the Adult Retreat which took place the weekend of January 21 to 24, 2005 in Boulder City, Nevada.

The center smiling face of my webbing (which you will see in the next newsletter) is me. And the lines leaving the smiling face are my free-flowing and un-organized thoughts about all aspects of the weekend. We, as a group, felt that this weekend was informative, diverse and, in some cases, provocative. Some of us were inspired by each other, and the research that Robert Shelton, as Executive Chairman, is trying to fund and initiate.

We had some wonderful trips. We went to the Hoover Dam, had a tour, and viewed some amazing achievements by mankind. (It is important to note, that these points were not on the web, yet the wording of the Hoover Dam was able to stir new thoughts while I am writing). We also went to Las Vegas; we all saw a show, and a couple of us stayed out a bit later to enjoy some of the more colorful entertainment that Vegas has to offer.

One of the most important parts of this get-away was the people. The folks that left a lasting impression on me are captured. Jr. or Cookie was from Maine and willing to share his thoughts with us; he is very wise for his young age. Throughout the weekend Cookie always showed his heart and feeling in a very true sense.

Mary Davidson greeted me on the bus ride out the Monastery. Mary is a friendly and warm person. She allowed me try and think through why I was here, and what I wanted to gain from the weekend. During the weekend, while Mary and the others were not in the room with us, she was very eager to hear our thoughts and conclusions when we immersed from our long sessions.

There was Dennis, very quiet and reserved. Unfortunately Dennis ate the mystery meat surprise. We did not know that the mystery meat was going to send Dennis to the hospital. When Dennis came back the next day, he for some reason chose not to eat the monks (our retreat hosts) delicate cooking again.

Bare, a very large man, who calls himself Bare. Bare has natural healing abilities. He makes and uses these very large tuning forks for this healing, and at times during this healing process, he nibbles and growls as well. Strangely enough, the area that Bare worked on for me, my lower back, still to this day does not bother me as much as before. He must be on to something. He openly shows his feelings, extremely straight forward in his questions, but throughout the weekend, Bare was always warm and welcoming.

Kathi Henry helped organize this weekend. I was not lucky enough to spend enough time with her, and to get to know her. From what I have heard, Kathi is a well-organized person and helped put this weekend together.

Robert Grace was one of the organizers for this weekend. He is a man with a great big heart. He tried his best to somehow join all these folks together. The first attempt at anything usually causes thoughts on how to improve and develop the original idea. This is now our starting point, and a very good point this is. As we develop the original idea, I would hope that peoples' input comes as ideas and suggestions and not as an attack.

For myself, I left this weekend behind me, believing that I would not be back. Yet opinions have changed before, and in my case will change again. During the weekend I learned a great deal. I realized that I was not alone on my island, but there are others that are there with me. And as my thoughts refined themselves, they gave way to true feelings and

more true thoughts of who and what I have become. The people I have met enlightened me. Hearing and knowing what they went through has allowed me to understand the thoughts and feelings that I had growing up. The trouble in learning in school was not my trouble alone. The un-organized thought patterns - I again was not alone. The speech issues, the knowing that I have things to say, yet I was not fast enough in my thoughts to be part of a conversation with others - I again am not alone. The feelings that I could not understand - I again was not alone.

Welcome to my island fellow KSers!  
For I am not alone anymore...

Thank you, LT

### KS&A Program and Volunteer Staff Changes

We have added two new directors: Director of Scientific Communications Services Lennie Wilson, MSN RN CS; and Director of Education and Development Ginnie Cover, MSW, MBA. Lennie's profile is highlighted in this edition of *The Even Exchange* so you can hear her story and better use the resources and skills that she brings to our growing organization. Ginnie will be profiled in the next issue.

There are also some changing of roles and hats among Program Coordinators. Stefan Schwarz has become the new "Variant and Mosaic Program Coordinator" and Paulette Rothacher has agreed to take on pediatrics as well as adolescents and is now the "Pediatric and Adolescent Coordinator." To assist her in her expanded role, Lauren Matthews, Sherryl Belinsky, Melanie Cashion and Leah Shelton have agreed to serve as Pediatric Program Assistants. Robert Grace, Adult Program Coordinator, has also signed on two new Adult Program Assistants, David Drexler and Zell Lundberg.

## 2004 / 2005 VIP VOLUNTEERS

KS&A gratefully acknowledges the generosity and commitment of those VIP (Very Important Person) Volunteers who, during the past year, have made generous contributions to the organization through their tireless service. Those VIPs who have graciously permitted us to publicly acknowledge their efforts are:

### Administrative and Support Services

Mary Davidson, Executive Director

Melissa Aylstock	Ginnie Cover	Robert Shelton
Sherryl Belinsky	Kathi Henry	Lennie Wilson

### Program Coordinators and Assistants

Jill Balfour	David Drexler	Leslie Petruk
Sherryl Belinsky	Robert Grace	Paulette Rothacher
Myra Byrd	Zell Lundberg	Stefan Schwarz
Melanie Cashion	Lauren Mathews	Leah Shelton

### 2004 Pediatric/Adolescent Conference

Paulette Rothacher, Conference Coordinator

Jill Balfour	Kristine Fredrick	Dennis Rothacher
Rashida Banerjee	Stephanie Fredrick	JoAnn Rothacher
Sherryl Belinsky	Vicki Fredrick	Mike Rothacher
Stacy K. Betz	Jay Giedd	Sharon Rothacher
Matthew Briles	Kathi Henry	Stephanie Sackovich
Marita Burrow	Dennis Kearney	Carole Samango-Sprouse
Liv Clasen	Alexis King	Stefan Schwarz
Helen Clements	Santina King	Leah Shelton
Linda Craig	Lauren Mathews	Robert Shelton
Mary Davidson	Scott Page	Lisa Storr
Winnie Dunn	Liz Raine	Cheryl Synder
	Alan Rogol	Mary Yeiser

### 2005 Adult Retreat

Robert Grace, Event Coordinator

Mary Davidson	Kenneth Herman	Paulette Rothacher
David Drexler	Edward Oleksy	Robert Shelton
Jennifer Grace	Jack Pool	Patricia Sullivan
Kathi Henry	Mike Rothacher	

### Spring 2005 Newsletter

Mary Davidson, Coordinating Editor

Jill Balfour	Leslie Petruk	Lloyd Tuckman
Sherryl Belinsky	Randall Rich	Lennie Wilson
Ginnie Cover	Paulette Rothacher	Kathi Henry
Robert Shelton		

### Scientific Advisory Committee

Heino Meyer-Bahlburg	Alan Rogol	Joe Leigh Simpson
Bruce Miller	Carole Samango-Sprouse	Ronald S. Swerdloff
C. Alvin Paulsen (Emeritus)		

### Board of Directors

Robert Shelton, Executive Chairman

Melissa Aylstock	Ilene Fennoy	Doug Lawrence
Sherryl Belinsky	Darrell Haag, Jr.	Carole Samango-Sprouse
Shiela Clark	Dennis Kearney	

### 2006 Adult Retreat Planning Committee (In Formation)

David Davis, Committee Chairperson

Mary Davidson	Zell Lundberg	David Wright
Robert Grace	Robert Shelton	

*We have made every effort to include in this list everyone who has volunteered for the organization during the past year and apologize profusely if we, even with our best intentions, have inadvertently omitted anyone. Out of the concern for space, all professional titles have been omitted.*

*continued from page 3 (Ped/Adolescent Conference)*

*and up.* A special thank you goes to Dr. Sprouse for making the extra effort to be with us at a time when there was a death in her family. We closed the conference with our visionary and compassionate Executive Board Chairman, Robert Shelton, encouraging everyone to get involved in KS&A and give of our time, talent and treasure to the X and Y chromosome community.

Six families of Triple X girls attended the conference for the first time. This was a welcome and long-awaited opportunity for them to meet and share their XXX journeys and partake in conference sessions. As we understand more about sex chromosome variations, it is increasingly apparent that we share so much in common. Except for one session on Androgen Therapy, the Triple X contingent agreed that the issues facing the XXY and XYY populations are very similar to their own. Speech and language delays are generally observed in the girls as well as sensory integration issues. A high point for these Triple X families was meeting with Helen Clements, founder of the first Support Group for Triple X families.

While parents absorbed conference presentations, we had GREAT volunteers directing the children's activities. The pediatric group had a fun time with Cognitive Workshops and a "field trip" to Hallmark's Kaleidoscope. My wonderful husband, Mike, spent the whole weekend with the adolescents! (I can't even imagine!!) They swam, played games, watched movies and went to Fritz's Railroad for lunch. Stephanie Sackovich had an enjoyable group session just for the teens. The lovely and generous Leah Shelton took photographs of our families free of charge. Please remember to contact Leah if you want to purchase additional pictures.

Judging from feedback from participants, the conference was a great success. I thank you all again for your involvement and investment in our kids and I hope to see you at our next conference! ***We all need each other to strengthen and uplift one another!*** And KS&A needs members to stay actively involved so the X and Y chromosome community gets the information, support, and research it needs and deserves.

**Paulette Rothacher, Pediatric and Adolescent Program Coordinator**

## 2004/2005 FINANCIAL CONTRIBUTORS

KS&A's efforts and achievements are fueled by the generous contributions and diligent efforts of numerous individuals, corporations and agencies. We gratefully acknowledge the generosity of those persons and groups who, during the past year, have made financial contributions to the organization. Those donors who have graciously permitted us to publicly acknowledge their support are:

### VISIONARIES (Over \$5,000)

*Richard and Rosalie Bregante*..... San Diego, CA  
*Robert and Leah Shelton*..... Coto de Caza, CA  
*Allcare Health Management System, Inc.*.....Fort Worth, TX  
*Solvay Pharmaceuticals, Inc.*..... Marietta, GA

*John and Gail Probst*..... Huntington, NY\*  
*James and Linda Seaton* .....Nashville, TN  
*David and Teri Lee Wedderspoon*..... East Windsor, CT  
*Michael and Deborah Wiener* ..... Alamo, CA  
*Lennie L. Wilson* .....New York, NY

### BENEFACTORS (\$1,000 - \$4,999)

*Anonymous* \*\*  
*Mary Davidson and Matt Seiden*..... Washington, D.C.

### SUPPORTERS (Under \$100)

*Anonymous* \*\*  
*David and Sherryl Belinsky*..... South Riding, VA  
*Thaddeus Bieniek*..... Buffalo, NY  
*Ian and Laura Black*..... Murphy, NC  
*Gregory and Wanda Bourgeois* ..... Gramercy, LA  
*Janie Bueter*..... Anchorage, AK  
*Charles and Barbara Gorga*..... Waldwick, NJ  
*Grace Griecci*..... Amherst, MA  
*Irma Linton*..... Abingdon, MD  
*Brent and Jeanne Reed*..... Shreveport, LA  
*Laura Webster*..... Georgetown, CA  
*Richard and Donna Zaugg*..... Lebanon, NJ

### SUSTAINERS (\$100 - \$999)

*Anonymous* \*\*  
*Mr. and Mrs. G. Kenneth Brobeck* ..... Washington, D.C.  
*Rammie A Frick* ..... Yorkville, IL  
*Amy Heit*..... Wayne, NJ  
*David and Anne Hewitt/Garrison* ..... San Diego, CA  
*Elizabeth Hirsch*..... Dallas, TX  
*Robert and Trudy Kladifko*..... Arcadia, CA  
*Ralph and Heather McCain* ..... Olathe, KS  
*John and Nancy Norton* ..... Petoskey, MI

*\*In loving memory of Matthew J. Probst.*

This is the first time that KS&A has publicly acknowledged individual donors by name. We are thankful for the substantial accomplishments during the past decade which have helped to overcome unfortunate errors and mischaracterizations in several early publications. By virtue of these achievements, and now that it is safer than ever before for us to take pride in our distinctive chromosomal make-up and what has been accomplished, we look optimistically to what lies ahead for this population. This list acknowledges those persons and/or groups who granted us the right to refer to them by name. Any donors who did not expressly grant such permission are acknowledged by the Anonymous listing within each relevant category.

## Upcoming Conferences and Meetings

### AAKSIS (American Association for Klinefelter Syndrome Information and Support) 2005 National Conference:

The AAKSIS Conference is scheduled for **Friday, July 29 and Saturday, July 30, 2005** at the Crowne Plaza Atlanta Airport Hotel in Atlanta, Georgia. XXY individuals of all ages, including those who are variants of XXY, and their families are the intended audience of this excellent conference program. There will be presentations by an outstanding group of speakers; private consultations with medical, educational and speech specialists; and support group meetings targeting a range of specific issues and needs. For more detailed information and/or to register, go to <http://www.aaksis.org/Conference05.cfm>, or call Roberta Rappaport at (888) 466-5747, or e-mail Roberta at [aaksis@sbcglobal.net](mailto:aaksis@sbcglobal.net) or Margaret Garvin at [ksobio@sbcglobal.net](mailto:ksobio@sbcglobal.net).

**KS&A Parents Conference:** We're thinking about holding for the first-time a conference directed to the needs and interests of parents of adults and older adolescents. This uniquely targeted meeting would likely be at a west coast location, with Los Angeles as a possible frontrunner and the timeframe, the spring of 2006. Taking advantage of things we learned at the January 2005 Adult Retreat, this meeting would focus on issues like health insurance coverage for adult sons, appropriate support systems after age 18, separation and autonomy issues during the twenties and beyond, sexuality across the spectrum, adult learning disabilities, research on X and Y chromosome variations across the lifespan, survivorship

and more. If you live anywhere in the greater Los Angeles area and might be willing to work on a planning committee, please contact Kathi Henry, KS&A's Executive Assistant, at (888) 999-9428.

### Regional Meetings:

Southern California Regional meeting is in the planning stages for later this year. Local members will be notified by mail; if you're interested in attending, watch the KS&A web site for more information.

San Francisco Bay Area 47XXY/Klinefelter Syndrome Support group on **Sunday, May 22, 2005** at 5:00 p.m. Carole Samango-Sproue, Ed.D., will talk about "sensory dysfunction in KS." For further details, contact Lauren Matthews at (415) 491-1738 or [Lauren@laurenandbrian.org](mailto:Lauren@laurenandbrian.org).

New York Tri-State Support Group is tentatively planning a half-day meeting in September or October 2005 with a focus on pediatric, endocrine and developmental issues. Watch the KS&A website for a posting about this meeting's date, time, location and speakers.

Several persons in the Dallas / Ft Worth, Texas area have expressed an interest in creating a new regional support group. We presently have eight individuals who want to hold a planning meeting. If you would like to take part in forming this group, please call or email Kathi Henry at (888) 999-9428, Ext. 21, or [KHenry@genetic.org](mailto:KHenry@genetic.org) and she will put you in direct contact with them and their effort.

*continued from page 1 (XXX Report)*

with understanding what is Triple X-related vs. the natural temperament of their child, not unlike other SCVs. Pre-pubescence and adolescence also bring about significant changes in our girls and many are bewildered at having to deal with a new set of socializing issues.

I believe it is a big step forward for KS&A to acknowledge all that we, representing different SCVs, have in common while also promoting research to learn more about each of our unique characteristics and concerns. Together all the sex chromosome variations (XXX, XYY, XXY, variants and mosaic conditions) constitute one large community of children, adults and families committed to understanding the challenges and opportunities that come with an extra X or Y chromosome. To that end, KS&A will be expanding and opening up the Listservs to more accurately reflect and embrace this philosophy. The Peds 0-3 list and Peds 4-7 list are opening to all SCV families. We have much to learn from each other. Creating active alliances among SCV families through our Peds lists and conferences will translate into real progress for us all.

The presence of the Triple X families prompted the medical researchers in attendance to take greater notice of us and entertain the possibilities of including the Triple X profile in their research investigations. As a result, several of us in attendance have contacted Jonathon Blumenthal, at NIH ([jonathan.blumenthal@nih.gov](mailto:jonathan.blumenthal@nih.gov)) to participate in the Brain Imaging study under Dr. Jay Giedd, principal investigator. The overarching goal of this study is to identify the relationships among genes, brain, cognition and behavior in children with sex chromosome variations. Another purpose is to better understand how these extra X chromosomes influence cognition and behavior indirectly through their effects on the brain. The study, began in 1999, will continue for many years.

Those in attendance at the conference in Kansas City also had the pleasure of meeting Helen Clements ([belenclements@hotmail.com](mailto:belenclements@hotmail.com)), the founder of the first Support Group for Triple X families in the world. Helen, along with her husband Graham, came over from London, England just to attend our conference and share her wealth of knowledge and experience with us. Membership in her Support Group is now over 270 families with registrants from all over the world. She continues to put out quarterly newsletters to her membership, sharing stories from families of girls with Triple X and reporting on their progress. It is always a welcome update!



The Yahoo Triple X Listserv (*raregeneticdisorders*) is thriving these days. There are now over 5000 archival messages posted. As this is the predominant Listserv for Triple X, the messages are geared to all age groups, pre-natal to adulthood. Information on the NIH study was broadcast through the Yahoo list. As a result, many families responded to the call and another coordinator was hired to handle the volume. Job well done!

Dr. Nicole Tartaglia from the MIND Institute in California, is also undertaking a study with the sex chromosome variation population. Dr. Tartaglia is a Fellow in Developmental-Behavioral Pediatrics at UC-Davis Medical Ctr. She can be reached at [nicole.tartaglia@ucdmc.ucdavis.edu](mailto:nicole.tartaglia@ucdmc.ucdavis.edu) and you can read more about the study and participation opportunities on page 9 of this newsletter. This study deals predominantly with the development, behaviors, emotions and medical issues of individuals with sex-chromosome variations. To date, approximately 13 participants with the profile of Triple X have registered. As in the NIH study, flight arrangements are made for participants, free of charge. Actual testing takes approximately 4 hours and consists of an interview, testing (to establish verbal IQ, performance IQ, visual and spatial learning) and completion of a questionnaire sent in advance of the testing date. A clinical component is also available to those participants wishing to speak with a medical professional.

The calls and general e-mail inquiries to KS&A continue to steadily grow. It is my pleasure to call families and speak to parents who have recently received an amniocentesis result of Triple X or families with daughters recently diagnosed with the 'extra kiss.' Our stories are all so similar and I believe most parents are relieved to discover they are not alone in their journey and are eager to search, learn and share as much as they can in order to give their daughters all the advantages they need to thrive. It is my privilege to be a part of their journey.

In 2005 I hope to see our community grow and we continue to make in-roads on the research agenda. I also hope we can get a better understanding of all the scientific literature that is published and put it together in an easy-to-read format. Ideally, a systematic or qualitative review would incorporate all the medical, psychological and behavioral studies. So much of what is available to the families about Triple X syndrome is sorely outdated, negative and not helpful. A compilation of high quality, useful and relevant information about 47,XXX is high on my wish list for 2005.

*continued from page 4 (Lennie Wilson, RN)*

professional, I created the Minds-On database in MS Access, and she converted my tables from MS word to MS access files. Today, after 6 years of mining information and research, I have roughly 6,175 articles. About half are full-text documents. The database also contains a list of books geared toward a lay audience and serving to improve health literacy for everyone and to inform us of the current work being conducted on the periphery of XXY. I have been working to make the database accessible to the KS&A membership and think [keep your fingers crossed] there is a way to bring the database to each of you. To be honest, KS&A is uniting us all.

I chose the name Minds-On to suggest that it takes many minds working with a single focus to address SCA, a partnership for wellness which must, I believe, exist if we are to remove the obstacles to the care and treatment of SCA. Minds-on is an analogy for hands-on and hearts-on. The Minds-On Database blends the skepticism of a scientist; the passion of an advocate; the creativity of educators, health and medical practitioners; the devotion of a parent; and the demands of the adult population.

The Minds-On database contains medical and non-medical literature and treatment strategies for **all** ages, including:

1. Nutritional and nutraceutical strategies, including essential fatty acid, zinc, micronutrients and estrogen detox.
2. Speech and language, occupational and physical therapies.
3. Protection from environmental endocrine exposures through food and water sources.
4. Central auditory processing disorders.
5. Play and activity therapies to promote socialization and prevent social disabilities.
6. Brain development and neurological rehabilitation.
7. Developmental dyslexia findings.
8. Studies on mood and temperament.
9. Obesity management.
10. Game play: the therapeutic use of games.

In 2003, I was accepted to Columbia University for a Doctorate of Science in Nursing and began work with four important courses; Genetics, Advances in Neuroscience, Advanced Pharmacology and Advanced Clinical Pathophysiology. Along the way, I will get a nurse practitioner certificate, allowing me to prescribe medicine and order tests. I hope to do a dissertation on temperament and mood disorders in SCA, adding to the descriptive literature and treatment strategies.

My work with SCAs is just starting. I continue to be inspired by adults and parents with sex chromosome variations and invite you to tell me your story and your observations. My being better informed will enable me to offer an even better informational database for you. I am focused on inspiring cogent scientific research; SCA knowledge building and brokering; exchanging information, articles and clinical resources; assessing clinical evidence and adapting it to the

## **Recruiting Individuals with X and Y Chromosome Variations (Sex Chromosome Aneuploidy) for Research Study**

*47,XXY (Klinefelter Syndrome)*

*47, XYY Syndrome*

*47, XXX (Triple XXX Syndrome)*

*45,X (Turner Syndrome)*

*48, XXYY Syndrome*

*And any other form of X and Y chromosome variation*

We are studying the developmental, behavioral, emotional and physical problems of children and adults with different X and Y chromosome variations. Our goal is to further describe the problems that commonly occur in these conditions. We also want to describe the medications that have been helpful in treating the behavioral and emotional problems in individuals with these syndromes.

Methods of the research include:

- (1) An interview and physical examination performed by the developmental pediatricians at The University of California Davis Medical Center M.I.N.D. Institute.
- (2) A packet of surveys and questionnaires about you/your child's development, behaviors, medical problems and medications.
- (3) A session testing fine motor skills, verbal skills, memory, reasoning and visual perception.
- (4) An optional blood test to study the genetic differences in individuals with anxiety, impulsivity, and other behavioral problems.

All people of any age with X or Y chromosome aneuploidy are eligible to participate. There are no direct benefits to the participants in the study. There is no financial compensation for participation in the study.

**For Further Information Contact:**

Dr. Nicole Tartaglia

Phone: (916) 703-0286

E-mail: [nicole.tartaglia@ucdmc.ucdavis.edu](mailto:nicole.tartaglia@ucdmc.ucdavis.edu)

Mail: Dr. Tartaglia, UCDMC M.I.N.D. Institute  
2825 50<sup>th</sup> Street, Ste 2322, Sacramento, CA 95817

Principal Investigator: Dr. Randi Hagerman

SCA; locating and using research-based evidence and other factors to shape decisions; and assisting KS&A in becoming the lead agency for SCA. In this way, I will fulfill my mission that began one day in November 1999. I am KS&A's Director of Scientific Communications Services – and nurse!

**Lennie L. Wilson MSN, RN, CS; Certified Clinical Nurse Specialist; Creator of the Minds-On Database**

(ECAC) office to prepare myself for this jump into the world of public schools and the land of IEPs. The schools in my geographic area are not known for their excellence (we are rated somewhere between the 48-50<sup>th</sup> of school districts in the country, about as bad as you can get). And I knew from doing my research that the district did not have any speech-intensive classrooms, which my son required due to his diagnosis of severe apraxia (in addition to being XYY).

Initially, I had decided that rather than fighting the battle of trying to get the district to provide the “most appropriate public education” (knowing they did not have an “appropriate” classroom) and fighting them to pay for tuition at a private school that provided the speech-intensive environment that my son requires, that I would simply request that they provide services for him at his private school. Our initial IEP went very smoothly – almost too easy. My husband and I, along with our caseworker and physical therapist through the Early Intervention Program, were all stunned as we left the meeting. A few weeks later, the phone call came. Our IEP had not been done correctly and changes needed to be made on the number of hours of requested services. This was presented as a minor logistical error but I knew that something “fishy” was up – and I was right.

Our second IEP was 7 hours long and the school district reversed its earlier decision, now saying they would not provide services at the private school even though they currently had therapists coming out to this school 3 to 4 days a week to provide services for other children. The Lead Educational Associate (LEA) representative, who facilitated the meeting, argued that their cross-categorical classroom was an appropriate placement for my son. Thankfully, I had audio-taped this 7-hour IEP (you must inform the school that you intend on doing this prior to the meeting) because the meeting ended in a deadlock; we were unable to come to any agreement and they refused to provide services for my son. I immediately informed the school I would be bringing an attorney to the next meeting.

Fortunately there is a Children’s Law Center in Charlotte and I was able to obtain the services of an educational lawyer at a nominal fee. She was at a loss as to why the school district was unwilling to provide services for my son. Additionally, my son sees Carole Samango-Sprouse, Ed.D., a specialist in conducting neurodevelopmental assessments, who has seen my son since he was about 10 months old. She agreed to conference call in to our next IEP meeting. We scheduled the IEP, had the lawyer present and Dr. Samango-Sprouse scheduled to give her professional recommendation. It took approximately 90 minutes for Dr. Sprouse to go through her report step-by-step and answer questions for the IEP team. When she concluded, the school district attorney asked to speak with my attorney. They were ready to deal. The school district now recognized they could not provide a “free and appropriate placement” for my son and meet his needs as previously proposed. The expert who knew my child best (Dr. Sprouse) was able to explain why he needed a speech-intensive classroom. And as a result, we have received *more* services

than we had originally asked for and the school district had until January 15<sup>th</sup> to either come up with a speech-intensive classroom or pay for my son’s private school.

After three more IEP meetings, each lasting between 4 to 6 hours, the school district unfortunately did not step up to the plate. They came back with an offer that they knew we would refuse but which showed an “attempt” on their part to provide an appropriate placement. Upon our attorney’s advisement, we agreed that we could not pursue due process (a court battle) because a judge might be convinced their offer was appropriate. However, together with other parents in the same boat, we are pursuing the possibility of a class action suit; helping us in this regard is the fact that two self-contained speech classrooms that did exist for elementary age students are being disbanded next year to pursue a more “inclusive” environment. While inclusion is appropriate and does work for some children, it is definitely not appropriate for all students ... my son being one of those.

So we have settled for speech-intensive services (which again were increased at the last IEP meeting) at our son’s private school for now. However, we plan on continuing to forge ahead to get the school system to do not only what is right for my son and many others like him, but what they are *required by Federal Law* to do! My husband and I recently visited another state for a job interview. I was amazed at the things I heard about their school district and their commitment to make sure that special needs children are given the best education possible. It saddens me that not all states have that goal in mind ... but I think as parents we can continue to aspire to and hold our states and school districts to this higher standard!

I share my story in hopes that it will help other parents. **You are truly your child’s best advocate!** I have been told by many professionals who are involved in these cases that when parents disagree with the school district’s recommendations, 90% of those parents just accept the school district’s decision/offer even though they know it is not in the best interest of their child. It is imperative that you know your rights (see [www.wrightslaw.com](http://www.wrightslaw.com) for great references regarding Federal laws supporting parental rights in getting special services for your child in public schools). And it is imperative that you use the professionals who know your child to advocate to supply your child’s needs. Additionally, I share my story in hopes that it will give some of you, who may be in the midst of the IEP process, some encouragement to hang tough and hold your district accountable for doing what they are required by law to do. Our children are entitled to a “free and appropriate education” in “the least restrictive environment.”

Due to space constraints, I have left out many of the details of the circumstances surrounding the eight-month process, the highs and lows and the many roadblocks and difficult people we encountered throughout the time period. Suffice it to say, it was an emotional roller coaster and incredibly exhausting! We had the LEA representative dismissed from our IEP



Leslie Petruk (KS&A XYY Program Coordinator) and son, Brandon

*continued from page 10 (XYY Advocating)*

team because she was so unreasonable ... most people aren't even aware it is their right to do this. To help you through this rigorous and trying process, look for organization(s) in your area that are there to shepherd you through the process. Every state is required to have a (Federal) program that assists parents in navigating the educational system for children with special needs and many states have trained advocates that can accompany you to your IEP meeting. Lastly, know your rights and fight for them! Your tax dollars pay for these programs. Your government requires a certain standard and your child deserves to have an appropriate education!

The payoff of all the time and stress was well worth the ride. My son has and will continue to pave the way for other children. The school system is no longer refusing services to other children at his school as they had been. All of the parents are banding together to continue the battle to get an appropriate classroom for children with speech impairment. We are even considering approaching the school district about opening a Charter School for speech-impaired children. Our battle has only begun, but my child is so worth the effort! He is my hero – his sweet gentle spirit, sense of humor and determination are what keep me going and remind me daily that his future is well worth fighting for!

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*KS&A is a non-profit 501(c)(3) organization dedicated to improving and enhancing the lives of individuals and families affected by X and Y chromosome variations. Our focus is on service and support to our members, combating the stigma promulgated by out-of-date and erroneous information concerning these conditions, and locating and helping to bring to market therapies that directly address the needs of persons living with these conditions.*

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*“Many persons have a wrong idea of what constitutes true happiness.*

*It is not attained through self-gratification but through fidelity to a worthy purpose.”*

Helen Keller (1880-1968)

**Thanks to Newsletter Contributors and Please Join Our Newsletter Team!**

We want to acknowledge the diligent efforts of Mary Davidson, our Executive Director, who filled in as Managing Editor of this edition of **The Even Exchange** and to the nine people who served as contributing writers. Kudos to all of you for a job well done!

As we complete this edition of **The Even Exchange**, we begin work on the next one. We encourage you to consider assisting with that or a future newsletter, either in terms of editing services or offering to write and/or share a story to help all of us live better, fuller and more productive lives.

If you're interested, please call Kathi Henry at (888) 999-9428, Ext. 21, and she will put you in touch with the Managing Editor of the next **The Even Exchange** newsletter.

Robert H. Shelton, Executive Chairman

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