

## What is an XXY Project Community?

Under the guidance of the XXY Project, an XXY Project Community is a group of two or more people in any geographic area who are:

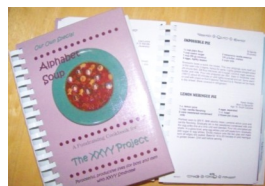
- Building awareness of XXY Syndrome and the XXY Project
- Building circles of support for boys and men with XXY Syndrome
- Raising money to support the XXY Project and their XXY Community
- Developing long-term care plans for adults with XXY in the area
- Providing parent education
- Organizing and fostering local gatherings
- Involving friends, family and other community members in the XXY Community
- Sharing new insights, findings and XXY information with the XXY Project.

More information will be available on our website throughout the year.

## XXY Project Information

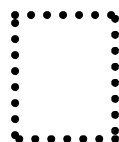
XXY Project Website	<a href="http://xyysyndrome.org">http://xyysyndrome.org</a>
XXY Library	<a href="http://xyy.batthish.org">http://xyy.batthish.org</a>
XXY Facebook Page	<a href="http://www.facebook.com/xyyproject">http://www.facebook.com/xyyproject</a>
XXY Twitter Page	<a href="http://www.twitter.com/xyyproject">http://www.twitter.com/xyyproject</a>
XXY Family Support Manager - Melanie Meyers	(215)394-5942 (8am-9pm, EST) <a href="mailto:inquiry@xyysyndrome.org">inquiry@xyysyndrome.org</a>
XXY Project inquiries - Linda Prudhomme, Executive Director	(310)910-3326 <a href="mailto:director@xyysyndrome.org">director@xyysyndrome.org</a>
eXtraordinary Kids Clinic appointments (including setting up phone consults with Dr. Tartaglia) - Susan Howell	(720)777-8361 <a href="mailto:Howell.susan@tchden.org">Howell.susan@tchden.org</a>

Clip and save!



### Cookbooks Still Available

Our cookbook fundraiser has been a great success. However, we still have over 200 books ready to find a new home! Visit our website to purchase yours: [www.xyysyndrome.org](http://www.xyysyndrome.org). (Click on Donate > Shop for XXY.)



Purposeful, Productive Lives  
For Males with XXY Syndrome  
PO Box 2172  
Littleton, CO 80161

## What is 48 XXY Syndrome?

48 XXY syndrome is a sex chromosome variation that affects one in every 17,000 boys who are born.

Males with XXY have two x and two y sex chromosomes, instead of one each. XXY is often mistaken for other syndromes. The most common symptoms and characteristics would be:

- Developmental delays
- Speech impairment
- Tall, considering family history
- Behavior outbursts & mood swings
- Learning disabilities
- Intellectual impairment
- ADHD symptoms
- Anxiety disorder / OCD or other mental health issues
- Autism, autism spectrum,

PDD-NOS

- Scoliosis
- Clinodactyly (Curved-in pinky fingers)
- Low muscle tone
- Flat feet
- Infertility
- Delayed sexual development / puberty
- Low or no testosterone
- Significant Dental problems
- Leg ulcers

(Not all males with XXY experience all of these symptoms)

Diagnosing XXY requires a genetic test called a karyotype. The test is done by drawing blood and an analysis is done on the cells of the blood to determine the boy's chromosomal make-up.



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# Double Male

Newsletter of the XXY Project  
A Project of the Colorado  
Nonprofit Development Center

A newsletter for donors, families and friends of the XXY Project

## Second Annual XXY Walk a Mile in My Shoes, A HUGE Success!

Spring 2011

### Charlene Welcome RN, XXY Walk Chairperson, and mom of Kyle - age 19

In the autumn sun and winds of November 2010, nine teams from around the world; consisting of more than 200 individuals of all ages; walked 1 mile to raise awareness of 48XXY Syndrome. In accomplishing that, they also raised over \$7000.00 in cash and prizes for the XXY Project - dedicated to raise awareness, educate, direct, and support males, their families and medical community to assist in leading purposeful and productive lives. There was a Halloween Parade, Prizes, Wine Tasting Event, Raffles, Family Gatherings, College Groups.....the response by ALL was totally overwhelming!!!

I would like to personally thank EVERY Business Sponsor and Individual from New York, Vermont, New Hampshire, Massachusetts, Pennsylvania, New Jersey, Indiana, Georgia, United Kingdom, and Washington DC for their time, energy, and donations to make this event such a success. I welcome you; yours; and all others interested in being part of this annual event that will be next held on 11/26/11 - "in a town near you".

For more information on how YOU can participate and/or help - please email [walkamile@xyysyndrome.org](mailto:walkamile@xyysyndrome.org)



## Announcing XXY Project Communities

In October 2010, the XXY Project Advisory board met in person to evaluate the current status of the organization and decide on the direction the future would hold.

After reviewing the results of our member survey, and advisory board members brainstorming and analysis, a major determination about the future direction of the XXY Project was made. The future direction involves a major restructuring of the organization and how it will serve our members. We determined that the XXY Project, as an international organization, will act mostly to empower our members to act within their own communities to serve their sons and our greater goals. To this end, the XXY Project will assist families in developing smaller groups in their own local or regional areas. These groups will be called XXY Project Communities. The idea has come from several other successful models being employed throughout the world to serve people with disabilities such as Circles of Support, PLAN, Innovative Communities, microboards, local support groups and others. XXY Project Communities draws from all of these ideas.



Advisory board members:  
Back row: Violaine Batthish, Maureen Miller, Brian Meyers  
Front row: Lynda Hall, Renee Beauregard

Each community may be different, depending on the needs identified by the community itself.

The XXY Project will provide advice and support on the development of the communities but those who build the communities will be responsible for them and their sustainability.

See back for more information on Communities

## Advisory Board

Lynda Hall

XXYY Parent Network Moderator

anxxyymom@aol.com

Maureen Miller

Chair

Secretary & Adult Services Committee

whizmobc@telus.net

Brian Meyers

Treasurer

brianmeyers5@yahoo.com

Violaine Batthish

Communications Manager

violainebatthish@rogers.com

## Staff

Linda Prudhomme

Executive Director

director@xyysyndrome.org

(303) 910-3326

## Key Volunteers

Melanie Meyers

Family Support Manager

inquiry@xyysyndrome.org

(215) 206-5836

Val Kellogg

Education Support

education@xyysyndrome.org

Ashi Daftary, M.D.

Janeen Daftary, R.N.

Medical Contacts

medical@xyysyndrome.org

Charlene Welcome

Roadmap to Services Committee

Walk a Mile in My Shoes Chair

walkamile@xyysyndrome.org

## Medical Director

Nicole Tartaglia, M.D.

## Renée Retires!

XXYY Communities is not the only big change at the XXYY Project.

Renée, one of the four founding parents, friend and mentor to us all, has retired!

She leaves behind big shoes to fill, and a legacy that will endure. She will be missed by the advisory board and parents for her tireless efforts, and we wish her the best in all her future endeavours.

Here are a few farewell words from Renée:

In 1998, I was the mom of a 16 year old with XXYY who had had very little in the way of support. I had found other organizations dealing with Klinefelter Syndrome (XXY) and had met, in person, only two couples who had a son with XXYY. On the Internet, I had posted an XXYY website and met up with three other families. With those three families, we started the XXYY Parent Network, our online support group.

Our "little group that could" began to grow and we started collecting information about our boys and men. We shared a lot of information back and forth between families. For a while, these conversations between parents constituted all of the accurate information that existed about XXYY Syndrome. I talked to many expectant parents, many parents of newborns, and other parents like me who had older boys and never had any support at all.

In 2003, one of the families in our group had an idea to have a get-together in Massachusetts, where 15 families met for the very first time. At that symposium, we decided that we needed an organization so that we could get others to help us to conduct research and provide help for our boys and the parents. In 2004, we applied to become a project of the Colorado Nonprofit Development Center, our fiscal sponsor, and I became the volunteer chair of our board and leader of the organization.

The XXYY Project has operated on the dedicated volunteer leadership of several parents since that time, until we hired Linda Prudhomme, who works very part-time for XXYY Project. These are big jobs that volunteers do, dedicating hundreds of hours of their time to improve the lives of our boys and men. I have had the honor of working with some of the best people I have ever met as a result of our shared connection.

I have recently resigned my role in the XXYY Project leadership, but the organization is in the hands of loving and capable people who are carrying our vision forward. As I leave this role, my one and only message to our families is this: please help our leading parents in every way you can. The XXYY Project, your son and all of our boys and men need you as we all continue to move forward. When the board tells you of all our new plans, invest your energy in supporting it. Give the time and talents you have for the benefit of all.

To all of our fantastic donors and supporters, I want to say thank you from the bottom of my heart for supporting the XXYY Project. You have made an enormous difference.

I wish everyone the very best and I will continue to be a member of the group rather than a go-to gal, but I am so thrilled that I have been on this journey with all of you.

If you think you might be interested in serving on the XXYY Project's advisory board, please send an email to [volunteer@xyysyndrome.org](mailto:volunteer@xyysyndrome.org) for more information.



## 2010 Symposium Reaching New Heights, Denver, CO

The 2010 Symposium is well behind us, but I cannot help but think back. This was my 4th symposium, and as always, I'm never disappointed. It is truly a good time to be had by all. I got to see some old friends, and make some new ones. I gave my first talk, and was overwhelmed to see all my peers show up to hear what I had to say. I participated in my first Mother's meeting, and it was great. The Dads self-organized and had their own time together, and from what I hear that was a success too! We had a group birthday party, with birthday card for everyone! But I have to say, the most fun time, as always, is the awards ceremony. I always get teary eyed, and nothing can replace the look on each of those boy's faces.   
 -Violaine Batthish



Award	Recipient
Most Outgoing	Alec Hall
Most Generous	Alex Daftary
Best Artwork on a CD Cover	Brad McEwan
Successful Independent Living	Dale Christofferson
Best Communicator	Harry Allison
Most dedicated student	Jacques Wiatrowski
Very Impressive Student	James Kocher
Greatest Gardener	Jason Stankiewicz
Fantastic Photographer	Jesse Gallantine
Most Courageous	Jon Coy
Expert Fisherman	Kaden Chamberlain
Health Improvement	Kyle Rupe
Academic Allstar	Brandon O.
Best Yard Helper	Austin Wilcox
Most Responsible	KC Corbitt



## New and Newsworthy 2011 is a busy year for the XXYY Project!

On February 17th, we held our first 48 XXYY Syndrome Awareness Day! Our Facebook and twitter accounts were alive with continuous facts and information about 48 XXYY, and our website had several tools available to help people raise awareness:

<http://xyysyndrome.org/raiseawareness.html>

We followed our first awareness day with 48 Days of Celebration.

This was a celebration of the lives of the boys and men with 48 XXYY, their families and the XXYY Project. Every day, for 48 days, we had a new story. If you have not had the chance to read these, please check them out at

<http://xyysyndrome.org/48daysofcelebration.html>

The XXYY Project would like to thank all the families who shared stories. Without you, this wonderful opportunity could never have happened.

The announcement and future launch of the XXYY Project Communities is another milestone, with more information becoming available throughout the year..

We also do not want to forget to mention that our wonderful Dr. Nicole Tartaglia and her husband welcomed their first child Louisa "Lulu" Rose Torrez, born on Feb 7th. Congratulations Dr. T!

The 2011 Symposium in Boston, Sailing Toward Success will be held July 14-17, we hope to see you there!

And in November, we invite you to Walk a Mile in My Shoes.

## Acknowledgements

The XXYY Project wishes to acknowledge the following special donations:

### In Memory of Frances Catherine Bondi

Christine Cardamone and William Dauksys  
William and Catherine Hyczka

### In Memory of Charles Stewart

Cornerstone Christian Church  
Ila Norman Frye  
Robert and Inez Dalton  
Jim and Ann Dockery  
Patricia and Harry Sapp

Richard and Lynda Hall  
Mark and Deborah Booz  
Leigh Munley  
Linda and Fred Neise  
Berenice Randolph