

Klinefelter Syndrome & Associates

Organization Info:

Name of Organization: KS&A (Klinefelter Syndrome & Associates)

Website: www.genetic.org

Address: P.O. Box 461047, Aurora, CO 80046-1047

Mission Statement:

KS&A's mission is to help individuals with one or more extra X and/or Y chromosomes and their families lead fuller and more productive lives.

Contact Person for Questions:

James Moore, Executive Director; jmoore@genetic.org; 303-400-1170 (direct to my desk)

Please check the most appropriate issue dealt with by your organization:

X Children _Elderly _Hunger/Homelessness _Disaster Relief _Animal Welfare
X **Health/Wellness** _Environment _Human Rights _X_ Families _Soldiers/Supporting
Troops

About Your Issue Area:

What is the deeper issue behind your organization?

1 in 500 individuals is born with an X and/or Y chromosome variation (officially “sex chromosome aneuploidy”). These individuals struggle in many ways, and virtually all need therapy, medication and other supports. But the complexities and expense of genetic testing, combined with low awareness of these conditions among medical professionals and other service providers, can lead to a lifetime of suffering, misdiagnosis and improper treatments, poor performance in school, inability to work, and many other difficulties. These conditions also are also associated with a 30-page list of comorbid conditions, which, with proper diagnosis, can be anticipated and caught early. Without diagnosis, these comorbid conditions often appear as unwelcome surprises in the lives of the individuals we serve.

What programs or services does your organization offer?

- ~ Semi-Annual Families Training Conference
- ~ Helpline and both professional and peer counseling
- ~ Online support groups
- ~ In-person support group meetings
- ~ Online library of resources
- ~ Fostering and directly supporting research
- ~ Education and outreach for medical professionals and other service providers

Do you have an interesting story to share with the students?

Recently, a teen who had 47,XYY, committed suicide after enduring years of bullying from classmates and others. This boy and his parents kept his condition a secret for fear that revealing his condition would lead to more abuse. In fact, however, by hiding his condition, they failed to take advantage of programs and supports available through the school that may

have offered him some projections from the torture he endured. Students and teachers alike were unaware of his special needs and so they failed to make necessary accommodations. School authorities were not attuned to this boy's challenges, and so they treated him like a typical student who was simply struggling socially. Our goal is to remove the stigma of these conditions and raise awareness that one or more students with these conditions attend virtually every school. It's no more acceptable to bully these students than it would be to bully a student who has Down Syndrome or a student who has a physical disability.

How Can Students Help?

How can students help through specific, tangible cash grants?

KS&A is a membership organization. Families and individuals with the conditions pay \$25 for an individual membership and \$10 for someone who has one of the conditions. Since families are often devastated by mounting medical bills, and since many children with the conditions are uninsured because these genetic conditions are considered "pre-existing conditions," many families cannot afford memberships.

KS&A will not turn anyone away, which means that we have many non-paying members.

~ \$25 would sponsor one parent to be a member of KS&A for one year;

~ \$10 would sponsor one individual with one of the conditions to be a member for a year.

How can students help through group service projects?

Our next families training conference is scheduled for July 26, 27 and 28, 2013 in Denver. Because families attend the conference and bring their children with them, we rely on supervised volunteers to assist with child care at these events. We typically require a minimum of 6 such volunteers.

Do you provide individual volunteer opportunities for youth?

Supervising others' children obviously requires some maturity and experience—perhaps as a babysitter. Since adult supervision will be provided, however, volunteers can serve in roles that are appropriate for individuals age 14 and up—with volunteers' parents' written permission.

Are there opportunities for students to be recognized by your organization?

Parents collect their children for lunch each day—to provide volunteers a break. We would be able to introduce and thank these volunteers during the plenary luncheons, acknowledge them in our newsletter, on our website, in advance conference materials, in the conference program and so on. Volunteers would also garner invaluable experience working with individuals who have these conditions and meeting others who are older and no longer require child-care supervision.