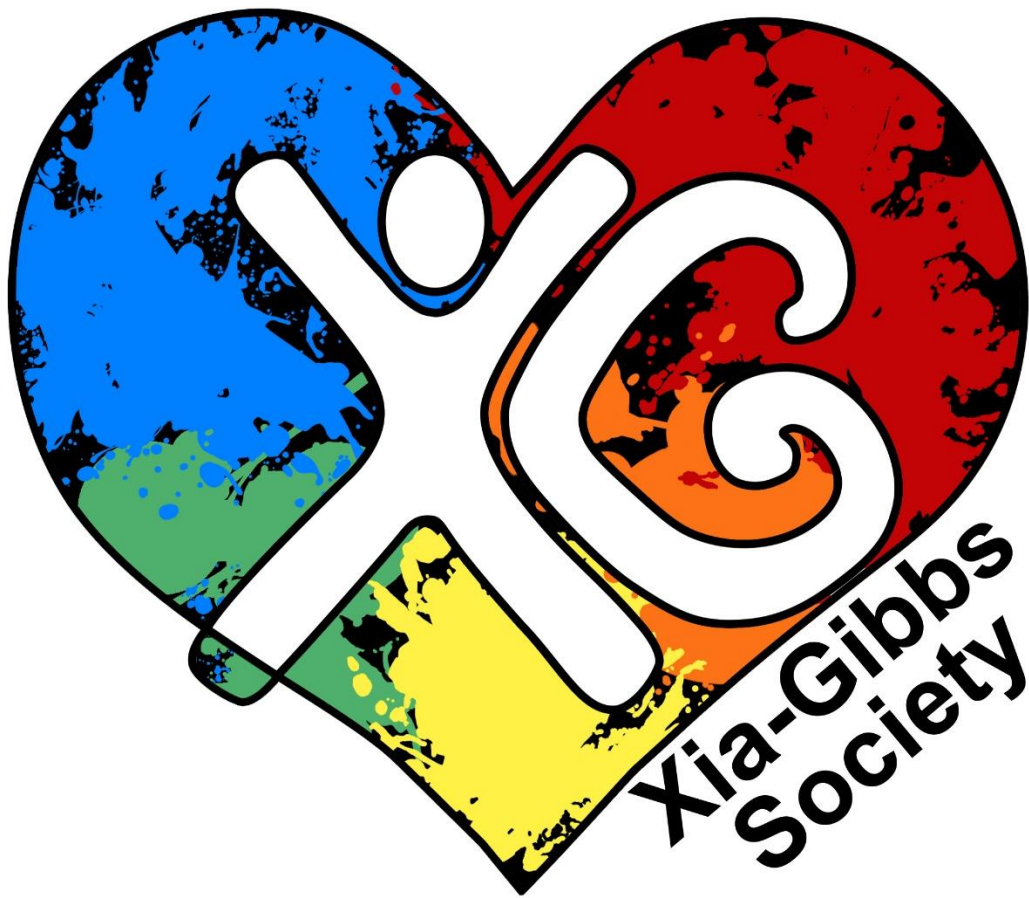


Fundraising Pack





So you want to raise funds for Xia-Gibbs Society? Thank you so much!

We would like to personally thank you for your time and dedication to our Xia-Gibbs Society. Fundraising for XGS will help to make a real difference in the lives of the individuals who have this rare syndrome.

Here is some information we put together to help you as you think about what kind of fund raising you'd like to do, how to run a fundraiser and how to communicate with your donors.

This guide will, I hope, prove useful as you start fundraising. Our goal is to help you maximize the funds raised by your efforts while also protecting you and the Society. There are many state regulations when it comes to fund raising so we want to ensure we stay within each state's laws.

Planning fundraising events and social media campaigns will play a vital role in helping us spread awareness. The funds that we raise will be critical to the Society and its aims.

Most importantly these guidelines will help us all stay consistent in the positive message that we deliver to the world about Xia-Gibbs Syndrome and the valuable work of our Society.

How can you make the greatest difference?

Believe in the cause and share the vision with others – your enthusiasm will catch on.

Be creative and think up new ideas or bring a new twist to an existing idea. Try to utilize what works best in your community, in your schools or churches. Just be sure to respect local COVID-19 guidelines to keep everyone safe!

Be realistic and don't set targets that aren't achievable or will stretch you too far. It's better to run a number of small and successful activities throughout the year than one large event that might stretch you too much.

Plan carefully. A simple timetable of what needs to be done, who is responsible for doing it and what the deadlines are will keep everyone on track and give an early warning of problems.

Use the personal touch. It is one of the great strengths of planning local events. Use your contacts and ask people to help. Most people are flattered to be asked to help, especially those who have close connections with someone with XGS.

Thank people for their help, their time and their money and tell people what their help means for XGS. A prompt thank you leads to loyal supporters.

Just know that the Board will be with you every step of the way. We appreciate your efforts and will support you in every way we can.

Starting a Fundraiser

The first thing to think about is what kind of fundraising you'd like to carry out...there are lots of great ways to raise money for charity, from sponsored activities, to donation drives, to fundraising events.

In the past, XGS fundraisers have run marathons, held fundraising drives in their community, held fundraising drives in collaboration with their local school, held t-shirt sales and created matching donations with companies who have corporate giving programs. These are just a few of the ways we work together to raise money for our cause!

Here is a great list of ideas we found that can get you started:

<https://blog.fundly.com/fundraising-ideas/>

And here is an example of a fundraising message that was posted in the past on a fundraiser's Facebook page:

Most of you know my daughter was diagnosed with Xia-Gibbs syndrome a couple years ago. Since then we have formed a very close community with the small number of families in the world who have been affected, and a lot of the parents are doing fundraisers to help raise money for the newly formed Xia-Gibbs Society. The Society has lots of aims, including to raise awareness and improve the information and support available for families, and eventually promote and fund further research. My birthday is on (date) and I would like all my family and friends to help me raise money! If you can't donate a simple share will work! Thank you all!!

Just be sure to respect local COVID-19 guidelines to keep everyone safe!

Feel free to communicate with us as you are working on your idea....there are some issues around certain kinds of fundraising (like raffles which are sometimes subject to gaming laws), so we can help you make sure what you are planning is ok!

Your next step in planning your event will be to communicate your idea to the Board in writing. You can email us at fundraising@xgsociety.org - we will then check all the charitable fundraising laws in your state to make sure we are okay to move forward.

Once your event is approved here are some simple guidelines to follow:

- **Keep in touch:** We ask you keep the Board updated on your event, especially any issues you might run into so that we can help you through it.
- **Identity:** Please make sure to use the approved logo and letterhead and follow guidelines of the charity name and logo.
- **Publicity:** If using local media to publicize your event, please contact the Board first for approval.
- **Insurance:** If planning an event that requires insurance please contact the Board.
- **Contracting:** Never enter into contracts or agreements on the Society's behalf without contacting the Board first.
- **Finance:** Maintain records so you can provide the Board with information about total amounts raised. Please make sure any money raised is kept in a safe or deposited into a bank, keep records of all donations, if possible, so that we can provide a receipt that can be used during tax time. The records should include first and last name, email address and phone number if possible.

What are we raising money for?

While you are running your approved fundraiser, you will want to communicate clearly with your donors about what you are raising money for and how the funds will be used.

The great news is we can help you with all of that! Here is some wording you can use to explain Xia-Gibbs Syndrome, the Xia-Gibbs Society and the work that we are doing:

FAQ's

What is Xia-Gibbs Syndrome?

Xia-Gibbs Syndrome (XGS) is a rare genetic disorder in which the AHDC1 gene is altered or missing. It usually arises spontaneously in the child and is not passed down by either parent. We now know that Xia-Gibbs Syndrome is a neuro-developmental disorder that originates in the brain, causing physical and intellectual disability. Many people experience breathing difficulties, sleep apnea and seizures. Many also meet criteria for autism and most require significant ongoing care.

What is the Xia-Gibbs Society, Inc.

It is a not-for-profit corporation formed in the USA for charitable purposes. The Society is here to support and advocate for those with Xia-Gibbs Syndrome (XGS) and their families, to raise awareness and to assist with scientific and medical research.

How will we use the donations?

The Xia-Gibbs Society aims to support ongoing research initiatives through direct funding, advocacy and through raising awareness about XGS. Scientists and researchers at Baylor College of Medicine in Houston and elsewhere are working on understanding the syndrome and trying to learn more about it. As they continue to conduct their research, we will hopefully be able to have more answers and more targeted therapies for those individuals with the syndrome.

One of the Society's goals is to raise \$50,000.00 in the next twelve months in order to establish a Research Fellowship, which would be awarded through a competitive grant process. In addition, the Society uses donor funds for other programs, for example our regular conferences at which persons affected by XGS can meet one another and learn from researchers, doctors and scientists who are working on the syndrome every day.

How do we collect the donations?

It's hard for us to collect cash donations because we don't have a physical presence in every location, but we have a bank account at Bank of America that you can deposit these into if you need to.

You can send a check or money order (payable to Xia-Gibbs Society Inc) to:

XGS Society
C/O Monica Pendleton
13402 Scenic Glade Dr
Houston, TX 77059

There are electronic options too:

Zelle (preferred method because we aren't charged a fee):

If your bank uses Zelle you can send/transfer money to xgsyndrome@gmail.com

Paypal:

If you have a Paypal account you can send your payment to email address ewilkinson@xgsociety.org

Or there are several online fundraising platforms which can be used. You might choose to use one of these so you can have a page dedicated to your fundraiser, with information and images specific to what you are doing.

In the past our donors have used sites like <https://www.gofundme.com/> and <https://www.everydayhero.com/au/> but there are several to choose from. Just be sure to check what

fees they charge so that you can be sure most of the money you raise will go to the cause you want to support. If in doubt, ask us and we'll look at it for you.

What else can we do to help you?

Please let us know!

We have access to images, logos, written materials and can create more...we want to work with you to make your fundraiser as successful as it can be, so just reach out for anything you need and we'll do what we can to help.

Thanks so much again for raising funds for Xia-Gibbs Society, we really appreciate your support!

Yours with gratitude, the Board of the Xia-Gibbs Society