



Xia-Gibbs Society

24th Board Meeting Presentation



Xia-Gibbs
Society, Inc.

Welcome! This is Your Society

What is Xia-Gibbs Society?

Xia-Gibbs Society is a not-for-profit corporation formed in the USA for charitable purposes.

Its mission is 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**.





This is Your Society

While incorporated in the US, Xia-Gibbs Society is an international organization, representing its global community through its activities in the US and in other countries around the world.

The Society represents all those affected by the syndrome, regardless of location.

Digital platforms have made this possible and have helped us grow the community to more than 435 families in over 49 countries.

The largest number are from America but our community extends throughout Europe, Canada, Australia, Asia and the Middle East.





Introducing Your Board

Emily Wilkinson, President, Board Director

Emily's role is to lead the organization, overseeing its operations and governance, ensuring its compliance with laws and regulations and driving its strategy and overall direction. She oversees everything the Society does and acts as its official spokesperson.



Monica Pendleton, Treasurer, Vice President, Board Director

As Treasurer, Monica is responsible for the finances and accounts of the Society, including its tax returns, and oversees the Society's state registrations. As Vice President, she deputizes for Emily. Monica is also instrumental in organizing the family conferences and managing relationships with corporate sponsors.

Arika Estep, Secretary, Board Director

In her role as Secretary, Arika is responsible for the Society's official documents, including bylaws, incorporation documents and board records. Arika also spends much of her time in the unofficial role of 'Head of Design' – she is responsible for all the Society's graphic content, including our logo, t-shirts, social media content and much more.

Introducing Your Board



Molly Nelson, Board Director

Molly Nelson has been involved with Xia-Gibbs Society since our first family conference in 2017 and joined the Board in 2020. She is involved in everything the Society does but notably was responsible for our Holiday ornaments campaign last year.

Kevin Wren, Board Director

Kevin Wren joined the Board in 2022 and serves as a director. In his professional life Kevin is an expert in online marketing and so we're very lucky to have him in charge of our email newsletters and associated campaigns.



Staff and Volunteers

Greg Wilkinson, Executive Director

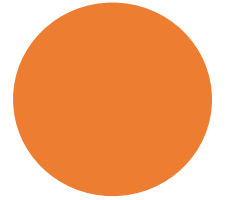
The Executive Director is not a Board position, but more like the CEO of a company. In this role Greg does anything and everything the Board needs him to do, including providing advice and support on governance and legal matters, proposing and overseeing new programs and fundraising campaigns, and assisting with financial reporting.

Karen Ballas and Gretchen Grundon, Grants Officers

Karen and Gretchen are Grants Officers, a new voluntary position we established this year to help us seek funding from other, larger organizations by applying for grants.

Special thanks to:

- Kjersti Dahl (FB group founder)
- Clare Daly (Instagram)
- Roberta Tino (Xia-Gibbs Italia)
- Dougal Johnston (Xia-Gibbs UK FB group)





Scientific Advisors

Dr. Megan Odgers is a small animal veterinarian practicing in New Jersey, as well as the mother of Cora, who has Xia-Gibbs Syndrome.

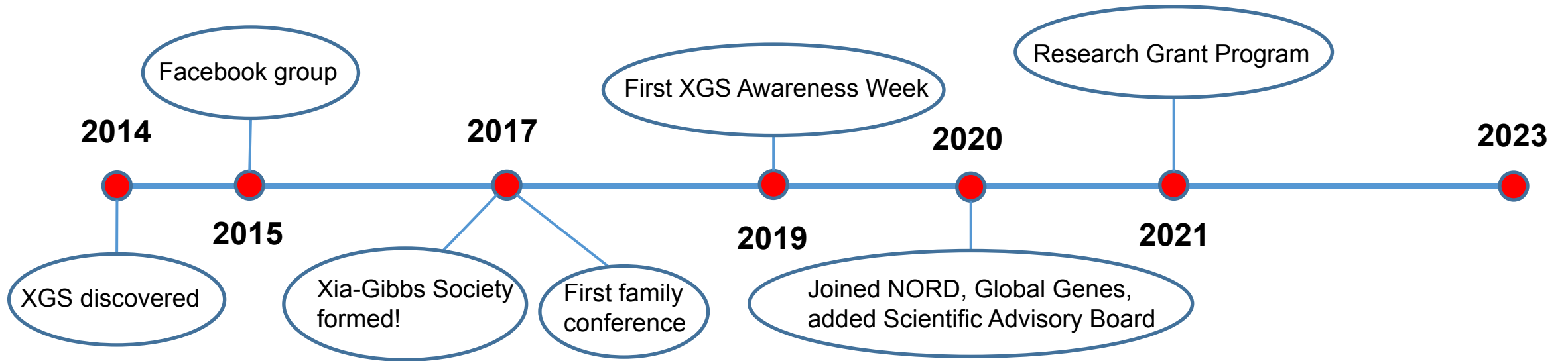
Dr. Wendy Chung, MD, PhD is an ABMG board certified clinical and molecular geneticist with over 20 years of experience in human genetic research of monogenic and complex traits.

Dr. Catherine Brownstein is an Assistant Professor in Pediatrics at Harvard Medical School and a Research Associate in the Division of Genetics and Genomics at Boston Children's Hospital.





Timeline





OUR IMPACT



437

Families



49

Countries



151

Registry Participants



150000

Research Funds

Family Conferences

Xia-Gibbs Society organizes regular Family Conferences, bringing together our Xia-Gibbs Syndrome community with researchers, clinicians, therapists and the Society Board. The experience for participants is often life-changing, as they are able for the first time to meet and speak with others living with this very rare condition.

Our Family Conferences were interrupted by the global pandemic, but we'll be back together again in Houston in **May 2024** – Mark your Calendars!





Research Grant Program

- Xia-Gibbs Society aims to award multiple annual research grants to support research into Xia-Gibbs Syndrome.

Xia-Gibbs Society Research Priority Areas:

- Furthering the basic understanding of AHDC1 function and expression.
- Gaining a more in-depth understanding of the varying clinical phenotypes and clinical presentations of those with XGS.
- Advancing insight into therapeutic interventions



Financial Reports 2022

Xia-Gibbs Society, Inc.
Statement of Financial Position
As at 12/31/2022

ASSETS:

Current Assets
Fixed Assets
Long Term Assets

TOTAL ASSETS

LIABILITIES:

Current Liabilities
Long Term Liabilities

TOTAL LIABILITIES

NET ASSETS:

Unrestricted
Undesignated
Board Designated
Property Plant and Equipment
Temporarily Restricted
Permanently Restricted

TOTAL NET ASSETS

TOTAL NET ASSETS AND LIABILITIES

Total to Date	Current Year				Prior Year
	Unrestricted		Restricted	Note	
	Operations	Board Designated			
\$85,678.58	\$85,678.58	\$50,000.00	\$0.00	1	\$78,642.57
\$0.00					\$0.00
\$0.00					\$0.00
\$85,678.58	\$85,678.58	\$50,000.00	\$0.00		\$78,642.57
\$0.00					\$0.00
\$0.00					\$0.00
\$0.00	\$0.00	\$0.00	\$0.00		\$0.00
\$85,678.58	\$85,678.58				\$78,642.57
\$60,678.58	\$60,678.58				\$28,642.57
\$25,000.00		\$25,000.00		1	\$50,000.00
\$0.00					\$0.00
\$0.00			\$0.00		\$0.00
\$0.00					\$0.00
\$85,678.58	\$85,678.58	\$50,000.00	\$0.00		\$78,642.57
\$85,678.58					\$78,642.57

1. Funding reserved for XGS Research Grant 2022/23



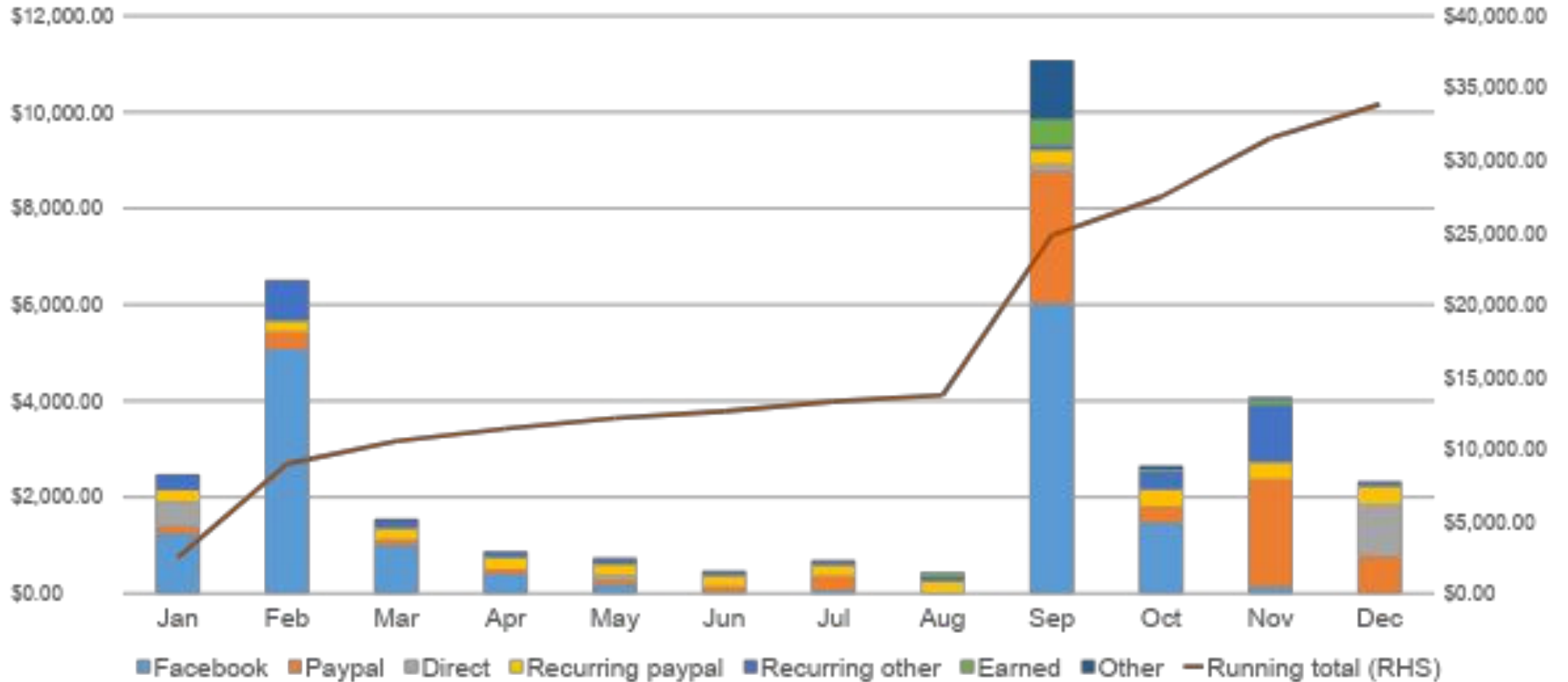
Financial Reports 2022

Xia-Gibbs Society, Inc.
Statement of Financial
Activity
As at 12/31/2022

	Prior Year	Current Year	Current Year Budget	% Budget to Date	Year End Forecast	Budget to YE Variance	Notes
Earned Revenue	\$42.37	\$773.68	-	-	-	-	-
Contributed Revenue	\$39,619.14	\$33,003.34	-	-	-	-	-
Released From Restricted	\$0.00	\$0.00	-	-	-	-	-
Total Unrestricted Revenue	\$39,661.51	\$33,777.02	-	-	-	-	-
	-\$50,000.0						
Program Expense	0	-\$25,000.00	-	-	-	-	-
Development Expense	-\$112.75	-\$917.35	-	-	-	-	-
Admin Expense	-\$2,423.66	-\$823.66	-\$3,000.00	-80.79%	-\$823.66	\$2,176.34	-
	-\$52,536.4						
Total Operating Expense	1	-\$26,741.01	-	-	-	-	-
	-\$12,874.9						
NET UNRESTRICTED INCOME	0	\$7,036.01	-	-	-	-	-
Restricted Contributions	\$0.00	\$0.00	-	-	-	-	-
Released to Unrestricted	\$0.00	\$0.00	-	-	-	-	-
NET RESTRICTED INCOME	\$0.00	\$0.00	-	-	-	-	-
	-\$12,874.9						
NET ALL ACTIVITY	0	\$7,036.01	-	-	-	-	-

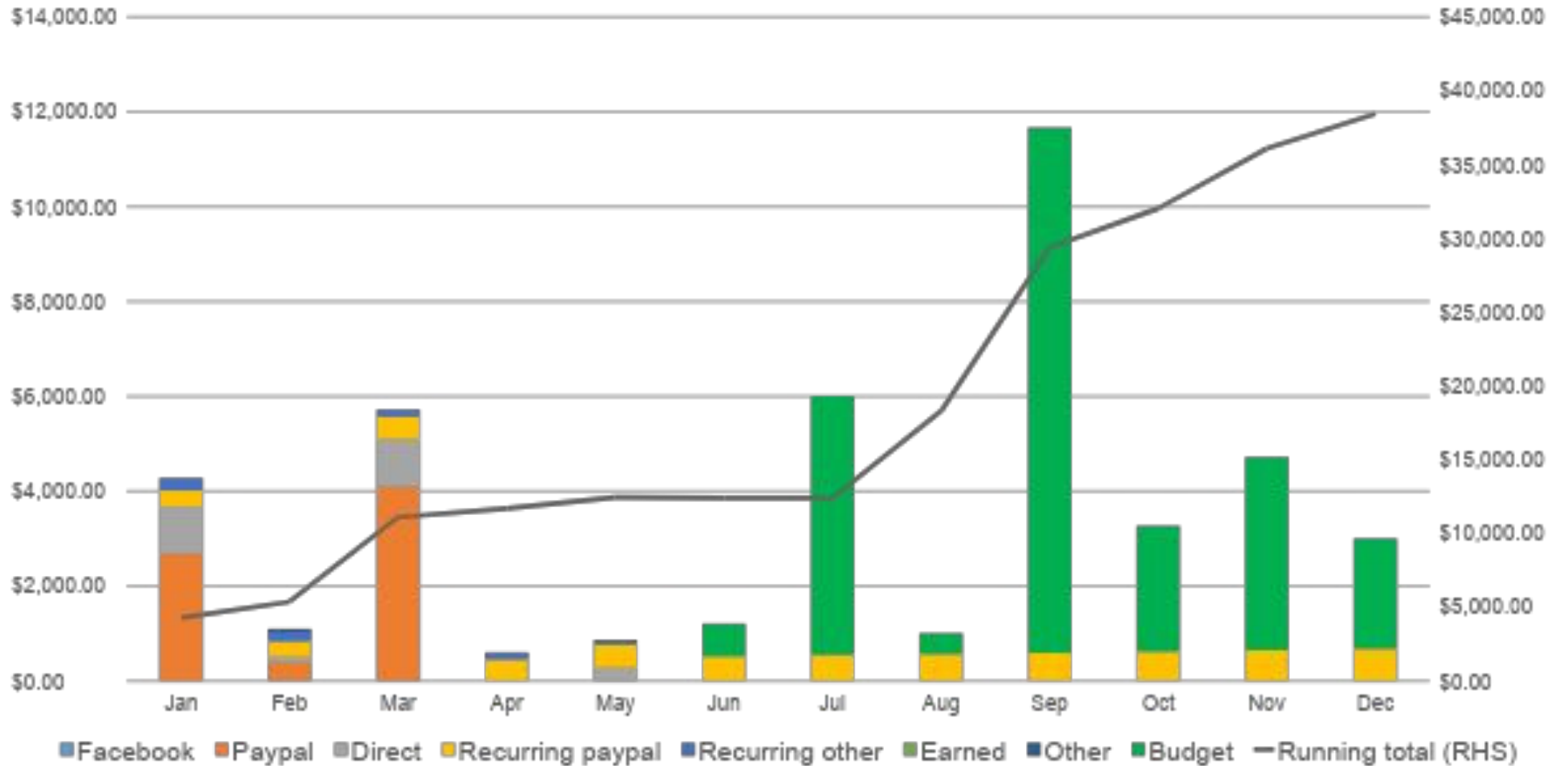


Revenue by Month and Source 2022





Revenue by Month and Source 2023



New Welcome Experience



We've implemented a new email collection form and welcome sequence.

We believe in respecting your inbox and keeping information relevant
Primary Caregivers and Loved Supporters

With this we are able to have higher engagement among emails
Higher engagement means higher deliverability!

With this experience, we've seen our list grow by 44%!
Above the "standard" of 22.5%

A screenshot of an email sign-up form. The form has a dark red background with white text. At the top right, there is a small white 'X' icon in a circle. The main text reads: "Sign up for our Email Alerts and stay in the know about everything Xia-Gibbs." Below this is a white input field containing the email address "kevin@xgsociety.org". Underneath the input field is the question "Are you a parent or primary caregiver?". At the bottom, there are two green buttons: "Yes" on the left and "No" on the right. The form is set against a background of colorful, abstract splatters in blue, red, yellow, and green.

Email Performance



Open Rate - People that received the email and opened it. Goal is to keep above 30%

Click Rate - People that received the email and clicked it. Goal is to keep this between 1-4%

Click Through Rate (CTR) - People that opened AND clicked the email. Truest engagement of the email!

Non-Profit Organizations enjoy a higher bump in these metrics as the base of recipients are more emotionally connected.

Campaigns

XGS Open Rate (Peer group): 49.4% (42.4%)

XGS Click Rate (Peer group): 7.03% (1.46%)

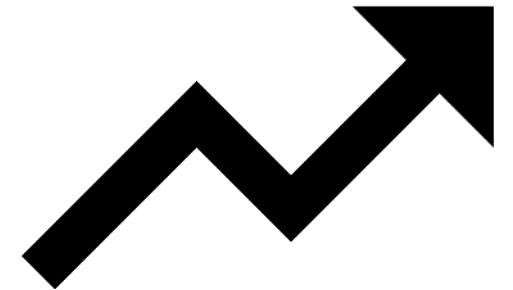
XGS CTR (Peer group): 14.2% (4.27%)

Flows

XGS Open Rate (Peer group): 55.2% (57.2%)

XGS Click Rate (Peer group): 7.46% (5.05%)

XGS CTR (Peer group): 13.5% (11.9%)



Where to from here?



We plan on using the channel as a stalwart purveyor of information.
The BEST way to get information to the society!

Look out for:

Monthly newsletters

Announcements

Reminders

Opportunities to help the XGS Research team!



How YOU can help!



Make sure to tell your WHOLE family and friends network to sign up for XGS Newsletters!

If you're not sure if you're signed up - head to the website and sign up!

Make sure to add XGS as a contact in your email contact list.

This will ensure all XGS emails land in your inbox!

Make sure to OPEN & CLICK every XGS email you see!



What's Next?

- Virtual 5k!
- Xia-Gibbs Awareness Week 2023
- XGS Family Conference 2024

