



# LIVING WITH XXY ANNUAL REPORT

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21



NICK RODRIGUEZ AND HIS FAMILY

Welcome to our first annual report as we celebrate our second year as a nonprofit organization.

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# OUR MISSION

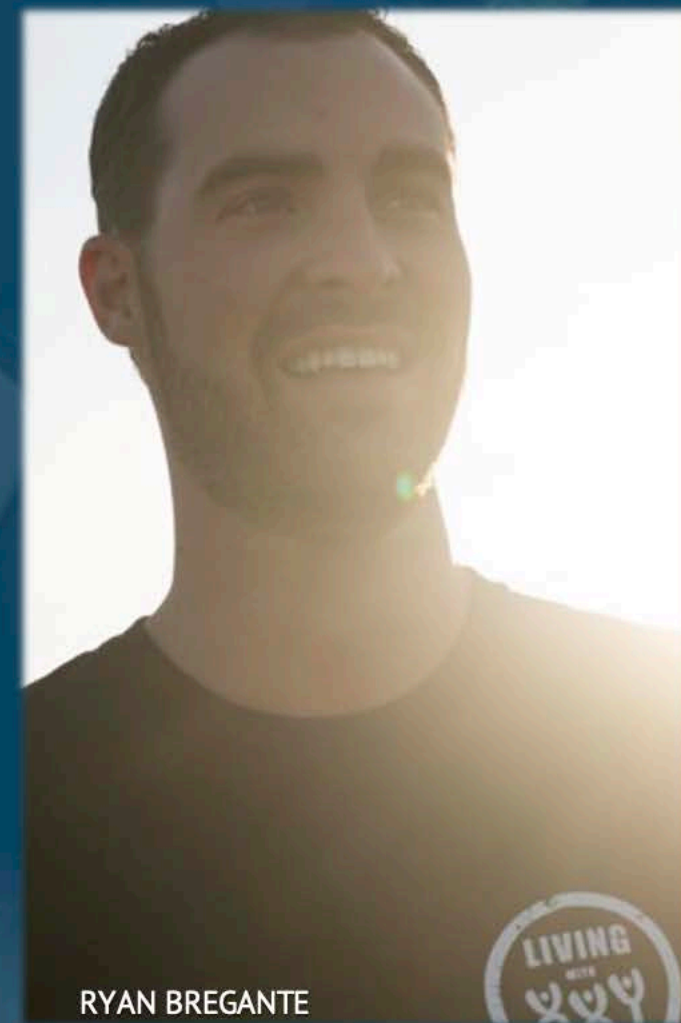


LIVING WITH XXY IS CHANGING  
THE WAY THE WORLD VIEWS  
KLINEFELTER SYNDROME (47, XXY).  
FOCUSING ON COMMUNITY, AWARENESS,  
AND POSITIVE TRAITS.

Today, Living With XXY represents a community of individuals, and families from 40 different countries, offering a positive outlook on life with an extra X chromosome. We have given a voice to those who have never been heard. In life, people always talk about finding their purpose to be a part of society and to give back to something greater than themselves. Upon starting Living With XXY, I too, was searching for my purpose in life.

Imagine looking into a mysterious, dark, and eerie tunnel knowing you must walk to the other side. Feeling scared and alone, you comfort yourself with the flashlight on your phone as you begin to walk into the darkness, eventually noticing a flicker of light that might be the exit. As you look back, you notice others following you, flashlights in hand as you lead the way. Every time you look back you notice more lights; a community is born. Walking together for quite some time, you begin to see the exit taking shape. Exiting the tunnel gives you the feeling of relief, and the confidence to keep pushing forward.

The **Tunnel** often feels like society is pushing down on us. The **Darkness** represents life's challenges, setbacks, and unknowns. The flicker of **Light** is the glimmer of hope to keep pushing forward. The **Flashlight** represents each person learning from experiences and successes along the way. The **Exit** symbolizes, The Feeling of Acceptance ready to share, educate and teach the world about what makes us eXtraordinary.



RYAN BREGANTE

Over the last year I have volunteered more than 4,000 hours to keep this dream alive for those who are trapped in darkness. Walking into the tunnel standing side by side, navigating together as we conquer society's stigma.

A clear and present vulnerability exists for our community. It's been close to 80 years since Harry Klinefelter in 1942 discovered Klinefelter syndrome. Each year, a staggering number of baby boys are wrongfully terminated, as prenatal testing becomes more available. Klinefelter syndrome is not a death sentence, nor something to fear.

Each generation of individuals has faced their own set of challenges and difficulties. With hard work and determination, our community has come a long way. We still have a lot of work ahead of us, but we're ready for the challenge. Those living with XXY bring the kindness, creativity, and empathy so desperately needed in today's world. We all deserve to live happy, healthy, and fulfilling lives. **"The stigma of the past will not take away the voices of the future."** – Ryan Bregante, President and Founder



2,700 NEW  
COMMUNITY  
CONNECTIONS



115 LIVES  
SAVED FROM  
TERMINATION



\$50,000  
RAISED

"Hi, Ryan! My XXY boy was born a week and a half ago, and I just wanted to thank you for all that you're doing! We were being led to believe termination was our only option, and then my husband and I found your Instagram. It has made accepting and advocating for our son so much easier and honestly changed our lives and has given us the tools to give our son the best possible life. THANK YOU" - Kori Fuchs

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## STAYING CONNECTED

YouTube Surpasses **1 million** views!

**8,200** YouTube Subscribers.

Website received **76,000** visitors.

Facebook followers **3,100** reaching **29,340** people.

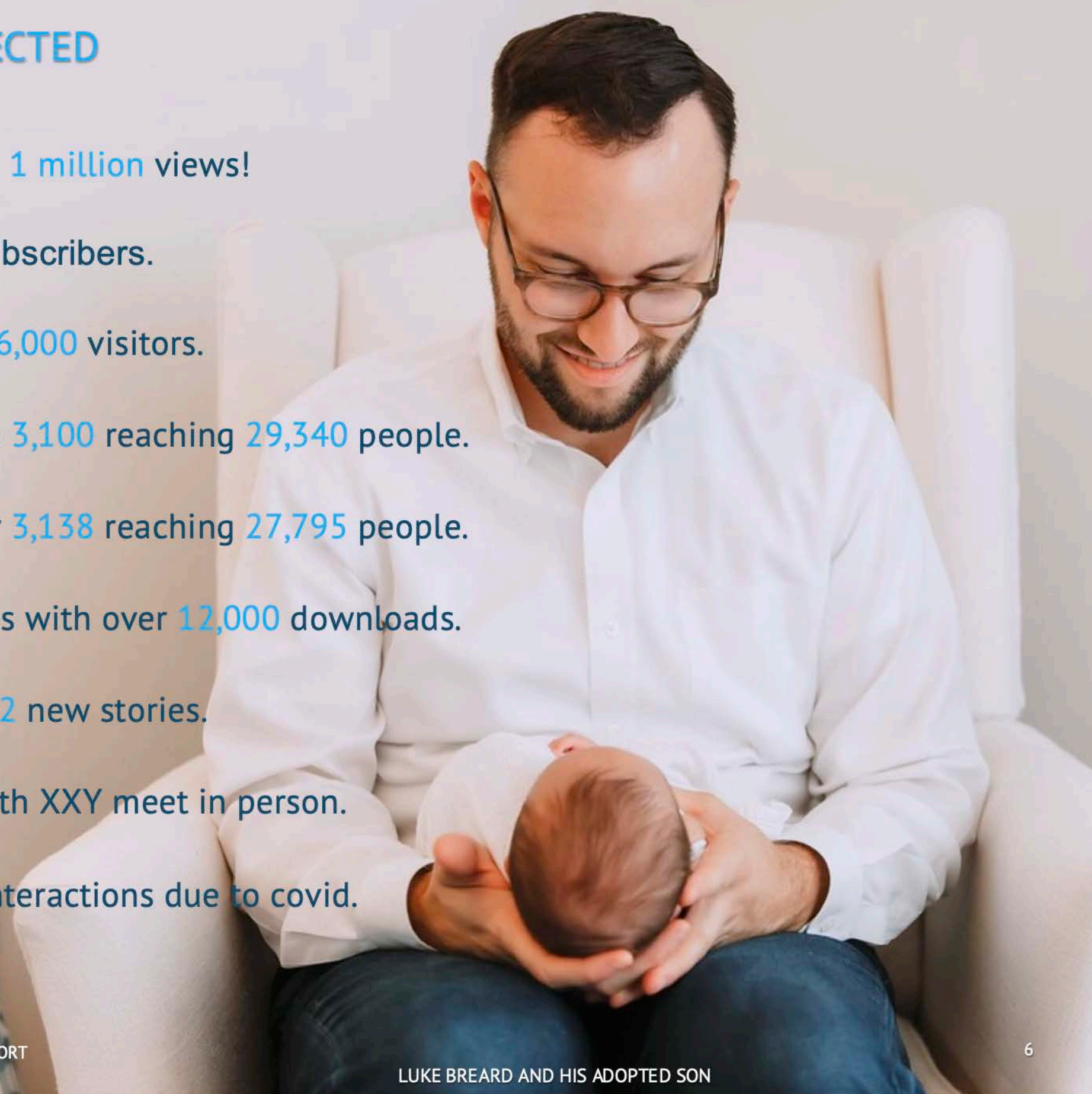
Instagram Follower **3,138** reaching **27,795** people.

**49** Podcast episodes with over **12,000** downloads.

Our Blog totaling **92** new stories.

**21** people living with XXY meet in person.

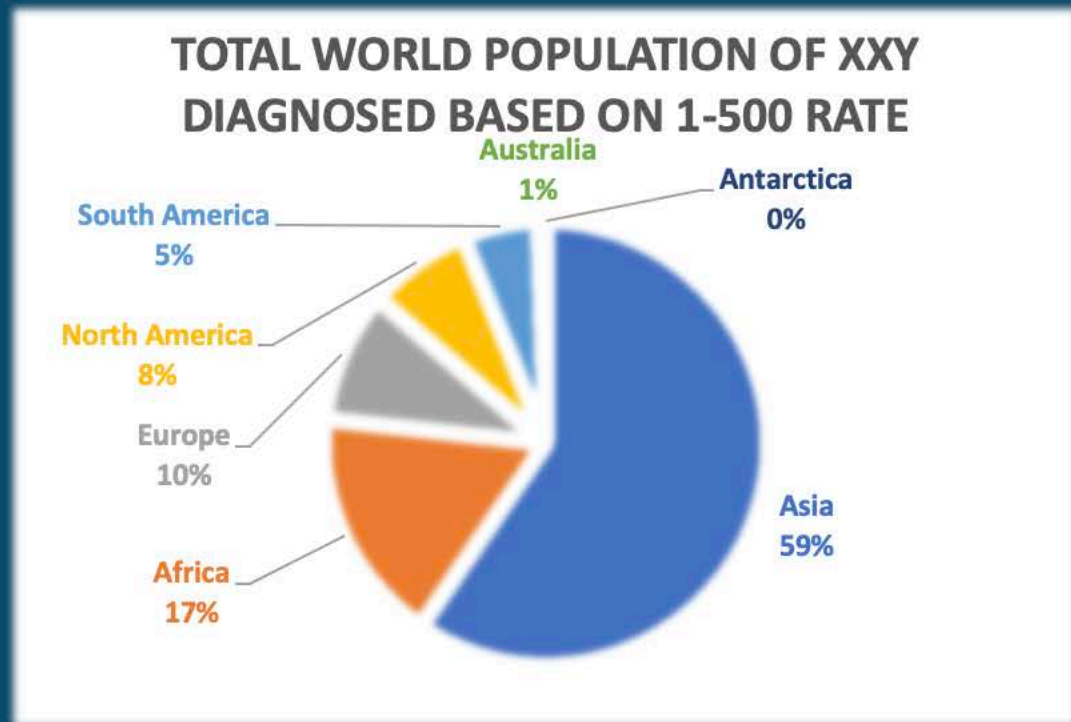
Only **17** personal interactions due to covid.



# CACLUATION BASED ON 25% DIAGNOSIS SUCCESS RATE

Current TOTAL Population			
1-500 Scenario		1-1000 Scenario	
XXY Cases	XXY Diagnosed	XXY Cases	XXY Diagnosed
<b>World Population</b>			
15,590,460	3,897,615	7,795,230	1,948,807
<b>Asia Population</b>			
9,282,110	2,320,527	4,641,055	1,160,264
<b>Africa</b>			
2,681,196	670,299	1,340,598	335,150
<b>Europe</b>			
1,495,272	373,818	747,636	186,909
<b>North America</b>			
1,184,145	296,036	592,073	148,018
<b>South America</b>			
861,514	215,378	430,757	107,689
<b>Australia</b>			
86,223	21,556	43,112	10,778
<b>Antarctica</b>			
-	-	-	-

Per Year Metrics			
1-500 Scenario		1-1000 Scenario	
XXY Cases	XXY Diagnosed	XXY Cases	XXY Diagnosed
<b>World Population</b>			
279,909	69,977	139,955	34,989
<b>Asia Population</b>			
147,592	36,898	73,796	18,449
<b>Africa</b>			
86,000	21,500	43,000	10,750
<b>Europe</b>			
15,318	3,829	7,659	1,915
<b>North America</b>			
8,651	2,163	4,326	1,081
<b>South America</b>			
20,917	5,229	10,458	2,615
<b>Australia</b>			
1,432	358	716	179
<b>Antarctica</b>			
-	-	-	-



## WHY WE ARE EQUIPPED TO HELP

### A. Website

We serve the community by ensuring visitors to our page receive the most up-to-date medical data, support services, and real-life stories of those living with KS. Our website is the landing page for those seeking accurate, conscionable, and true-to-life information about Klinefelter syndrome.

### B. Fertility Project

Infertility is a hallmark symptom of KS, however there's not much information on the internet specifically geared towards men about ways they can grow their family. We've created up-to-date and accessible resources about sperm donation, Assisted Reproductive Technologies, adoption, and the micro-TESE procedure.

**C. Our President and Founder, Ryan Bregante,** is a man living with Klinefelter Syndrome/ 47 XXY. We understand what living day to day life can be like, and that it is more than just a medical syndrome. Ryan also participated in active research by the NIH. Also, public speaking at New York University and Hunter College.

### D. Early intervention guide

Early interventions such as physical therapy, occupational therapy, and speech therapy are critical to helping many boys with XXY stay on track developmentally. We've created an extensive and up to date (as of 2021) list of early intervention programs by state to assist families in navigating the services available in their states.

### E. Constantly connected

We have a thriving community of families that our team of staff are constantly in contact with. There are thousands of boys and men across the globe that we support with our education and outreach.





## F. Adapting research papers

Much of the information about Klinefelter syndrome is written in unapproachable or intimidating scientific jargon, so our team developed a “CliffsNotes” version of four scientific research papers. These abbreviated documents written in a more approachable language means we are better able to get current information about KS to a broader audience. These documents are on our website, as free and accessible resources to the public.

## G. Working with Getty Images

Photography of boys and men in real life situations widely available to the public and to help replace outdated photos on google. This will help others understand this is a spectrum and we lead normal every day’s lives.

## H. Blogs and stories

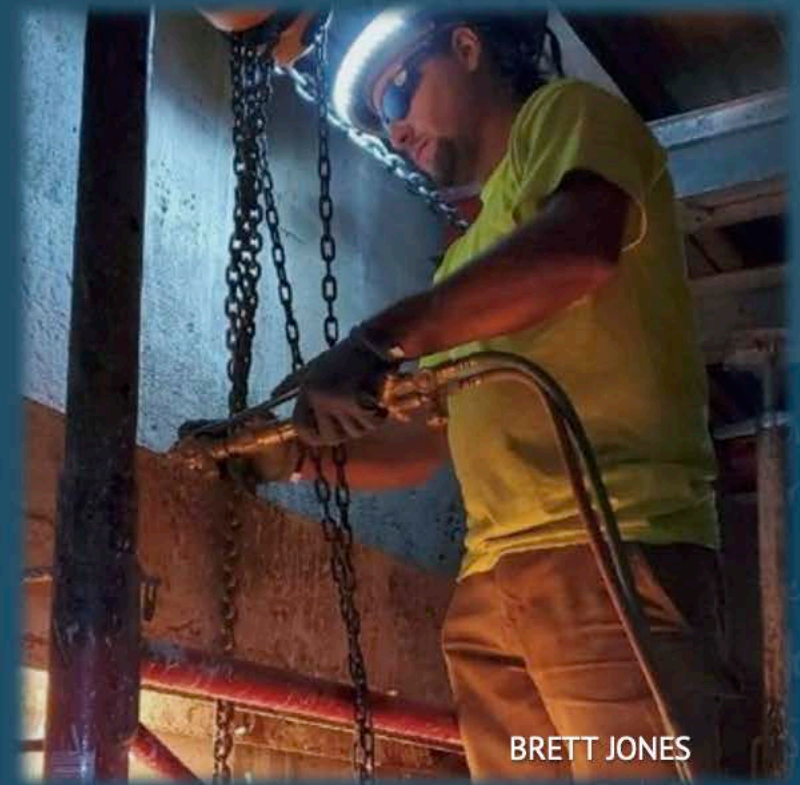
We share the stories of those living with their XXY diagnosis. The community is full of boys and men living meaningful, successful lives.

## I. Podcast and Documentary Series

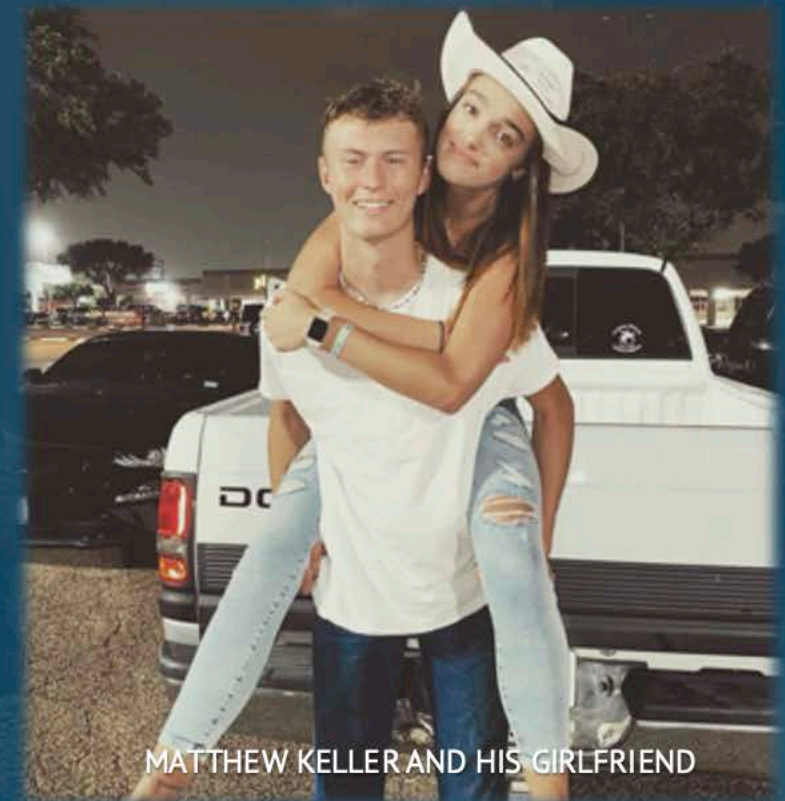
Come behind the scenes with us in a no-holds-barred podcast with Ryan Bregante as the host. From testosterone replacement therapy to prenatal diagnoses, and everything in between, Ryan tackles all the hard topics to help bring awareness and understanding to what it’s like to live with XXY. Our documentary series takes viewers into the homes and lives of individuals living with Klinefelter syndrome. Honest, emotional, and informative, this series shows the truth about what it’s like to live with the most common chromosomal variance

## J. Social Media

We have the largest social media presents for Klinefelter syndrome with over 1 million YouTube views. We are very active on Facebook, Instagram, LinkedIn, Twitter and TicTok.



BRETT JONES



MATTHEW KELLER AND HIS GIRLFRIEND

# WHAT IS STANDING IN THE WAY?

## The Misinformation

Stigma is a badge of shame that sets a person apart from others. When someone is labeled by their diagnosis, they are no longer viewed as an individual. Klinefelter syndrome/47, XXY is unknown to most of the world and presents on the spectrum. One of the more significant issues is that Klinefelter syndrome covers a range of issues. Very few people know how to help best.

**"Not rare, but rarely diagnosed" Emily Waddie.**

### A. Google

When you search for Klinefelter syndrome, there are a lot of outdated, old, and inaccurate websites that come up. These websites are often inflammatory and sensationally utilize XXY for their agenda. Information is very harmful and only talks about health-related issues, educational problems, and not a single thing about our positives. People are afraid to raise awareness, to self-advocate, and to submit themselves to the information. People are taught to believe this is a syndrome that creates an insurmountable challenge.

**"The typical bullet points always come up on easy-to-find websites describing XXY. One bullet point you see often is that We have a "small penis" and grow "male breast tissue." It would be better to say things like "smaller penis size" or "could develop breasts." When people read that some of us can have small penises, the information becomes problematic when telling others, you have XXY." Charlie Bry**

### B. Physical Representation

Photos do not show the spectrum of individuals. XXY affects people in various ways and there is more than one body type. Numerous images have black stripes through people's eyes, with no human feeling. Illustrations can be very exaggerated.



ROBIN AND DYLAN MATHIS

### C. Lack of Awareness, Advocacy, and Education materials

The feeling of shame can lead people to never become open about their diagnosis. Most available information describes the problems of Klinefelter syndrome, which can be overwhelming. Between 1-400 to 1-650 males are born with Klinefelter syndrome. Only 25% will receive a diagnosis during their lifetime, while 75% will die never knowing. There are inadequate resources to help kids and adults learn and how their brain functions. It isn't easy to access services, and there is no specific information for executive functions, mental health, depression, anxiety, and ADHD. There is very little understanding within our community about the spectrum and how others might be affected. Very few understand their diagnosis, and do not seek help till major issues become present.

**"No one recognizes our condition and therefore they don't give us the time or space to be understood. I wish there was more accessible information for everyone."**

**Kyle Lorts**

2. Humans have how many chromosomes in the body cells?

A) 23

B) 46

C) 50

D) 72

I have 47 ;)

### D. Social Media

In today's world social media is everywhere, and people spend countless hours scrolling. However, with this consumption of social media comes spreading of harmful misinformation, including mislabeling and misrepresentation of Klinefelter syndrome.

THE WINNER-WINDET FAMILY



BROTHER AND SISTER

## E. Addressing Male Infertility

The overwhelming majority of men with Klinefelter syndrome face infertility. Male Infertility stigma is a phenomenon connected with various psychological and social tensions. The stigma is associated with a feeling of shame and secrecy. In many cultures, male infertility remains a stigmatized condition related to a lack of virility and masculinity.

**“At the time of my diagnosis, infertility was one of the hardest aspects to come to grips with it. I was in a relationship, and the plan was to start a family so that diagnosis fractured our relationship, which led to my divorce. It hurts the most, I think, as I do feel less than worthy, less overall.” Miles Welch**

Many of the men in our community have found out they have Klinefelter syndrome when trying to conceive. When we asked them what they felt after receiving their diagnosis, this is what they said:

- “I had a lot of anger; it crushed me and gave my mental health an absolute smacking. I was given lots of unhelpful advice.”
- “I was pissed off when I found out that I couldn’t make kids.”
- “I was worried about what society will think of me, and it felt like an earthquake was happening beneath my feet.”
- “Original feelings about KS were as simple as the loss of self-worth because I couldn’t give my wife what she truly desired.”
- “Complete and utter sadness that I potentially won’t be father to my DNA children.”
- “Anger and fear were prevalent during the first two years until I adjusted.”
- “Feeling less of a man, I hated myself.”
- “I spent my life shutting down relationships and walking away. Torment, hurt, and unworthiness.”



## F. Medical Industry

Healthcare providers are not well-versed in Klinefelter syndrome/47, XXY. Therefore, it is up to the community to become the experts to ensure they get the best medical care available. Navigating this can be difficult for members of the community. A research study done in 2010 suggested that 70% of babies in utero are terminated each year in the United States and 87.5% in Canada. The limited available research focuses on inabilities and medical health issues, not accurately representing the positives and spectrum of the diagnosis. Professors and medical textbooks teach the next generations of doctors and providers misinformation, reinforcing the stigma we are trying to change.

How healthcare providers share information is critical to how patients receive and understand their diagnosis. Parents carrying an XXY pregnancy are not receiving accurate information. Many healthcare providers profess to have never heard about it, leading them to google resources, and traumatize expectant parents with horror stories about their unborn son's future.

Many boys and men are unable to get the correct testosterone replacement therapy covered by insurance companies, or are denied treatment by their healthcare providers. The hoops they must jump through to receive the proper medical care necessary to live full, healthy lives are outrageous. Testosterone is as important to a man with Klinefelter syndrome as insulin is to someone with diabetes.

When we asked our community about healthcare, these are some of the few things they have said.

- “Lack of research, insufficient clinical trials, and knowledge on what to study.”
- “Doctors have told me they have never met anyone with KS, and they only read about it in medical school.”
- “Complete lack of knowledge and ignorance on every level. We must travel cross country to find experienced doctors.”
- “My son's psychiatrist told us our son would be weird and would have bizarre sexual interests.”
- “I told my doctor I have Klinefelter syndrome. Her response was “Are you sure?””
- “Every time I go to the doctor, they ask me if I am gay and every time I tell them no, I am not gay.”



## THE FOCUS ON COMMUNITY

Our goal was to create a safe, inclusive community where people can talk, connect, and feel safe to share their struggles even if they are not open to the world. We plan to continue to create environments that allow members of our community to freely express themselves, have access to accurate, up-to-date information, and can connect with others like themselves.

Hi! I just wanted to take a moment to say thank you for having this resource! My husband and I just got the results from our amniocentesis that our sweet boy (due in March) is XXY. Your page has put a lot of our anxiety at ease and given us hope that our little guy is going to have a fulfilling, happy, and amazing life 💙 Looking forward to joining the community and being a part of it.

I know for sure you helped me. And, helped me accept my diagnosis. I grew up not knowing and based on what I read, I did not feel it represented me. But after seeing you and hearing you in your videos when you first started, I could relate to you. And through what your message was I finally began to listen. You saved my life, thank you so much!

Loving your stuff! I use to not care about my KS. Life has change a lot though. I don't really want to start my own thing to advocate for KS. So, instead how can I help?

Hi Ryan, Ive been listening to the Podcast and they all have been so helpful!

Great site! My 32 y/o son was diagnosed at age 26 after a lifetime of struggle and put downs. Imshooting him this infor for support. Keep up the amazing work!

Hi I have just seen ur YouTube video I have just found out after 2 years of trying for children I have an extra x and obviously looking into it and being told so many things ur a inspiration

Dude, I love your YouTube videos on how to preform testosterone injections. They have been a GOD sent for me.

Thank you for all you are doing. (I dont think my husbands parents have even grasped the reality of his diagnosis) Awareness is so key! Thank you

## JAKE'S STORY

Jake's diagnosis came after his wife started having pain. She'd been taking an exercise class and had a concerning pain in her chest. She made an appointment right away and was diagnosed as a carrier of spinal muscular atrophy. Since the couple had been talking seriously about having children, Jake decided to get tested to ensure he wasn't a carrier as well. If he was found to be a carrier, their future children could be at risk, so finding out in advance was prudent. He was not a carrier, but the doctor did find a genetic anomaly and decided to run a karyotype test. Jake had 47, XXY. He was stunned. He was tall and athletic and had served time in the military. How could he have low testosterone levels? When the doctor explained the likelihood of him having his own children was extremely poor, Jake was crushed. He told his wife, and she was stunned, as well. Though he'd gone to get tested, he was a healthy young man and neither of them anticipated him having any issues.



These days, Jake is happy. He works for the FBI in the cyber division and has recently accepted a promotion. He and his wife are planning a family and are excited to go through the process of having children. Jake is working on fully accepting his diagnosis but has come a long way. When asked why he chose to participate in this interview, he spoke of helping others who are dealing with finding out they have Klinefelter syndrome. "My advice would be to remember who you were before the diagnosis. You are the same person; it just takes a little time to accept it." As he warmed to the subject of helping others his confidence grew and his face lit up. "I like the idea of being able to help someone else with my story. To let them know they can reach out to Ryan, me, or really anyone in this community, because they have so much empathy, and can give you information." Doing research has been important too. Having been surprised by Klinefelter syndrome twice in the past, he's not going to let it happen again. Jake has investigated aging while living with XXY and is well-versed on what the future may hold.

# A FEW OF OUR AMAZING FAMILIES



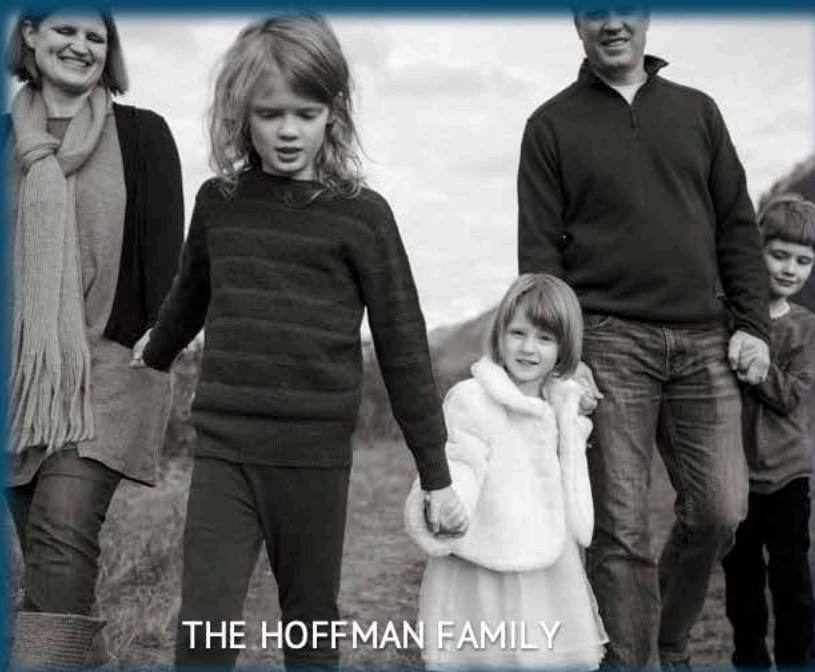
THE ANGELBECK FAMILY



THE KELLER FAMILY



THE GULLIVER FAMILY



THE HOFFMAN FAMILY



THE CURRY FAMILY

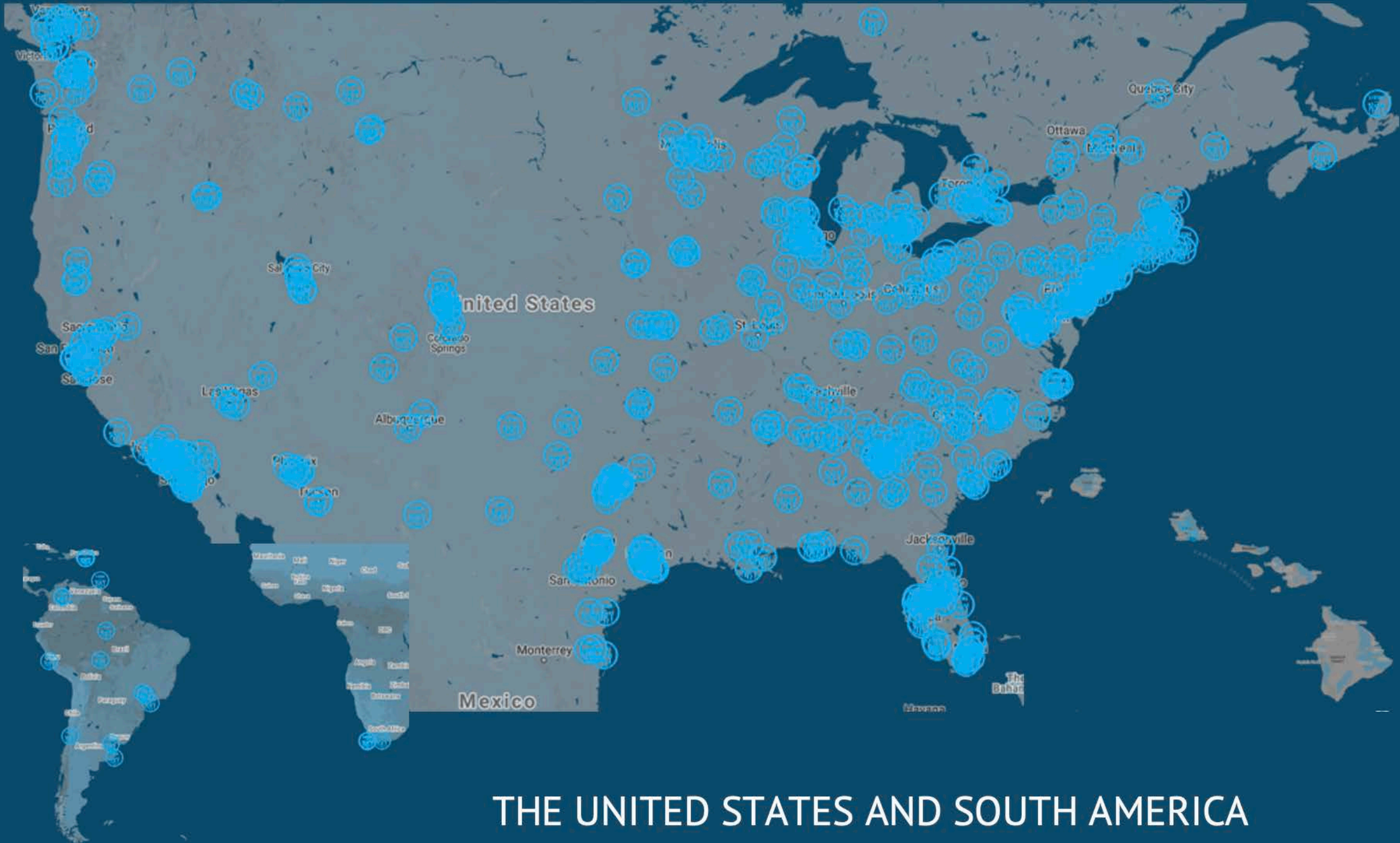


THE BARRETT FAMILY

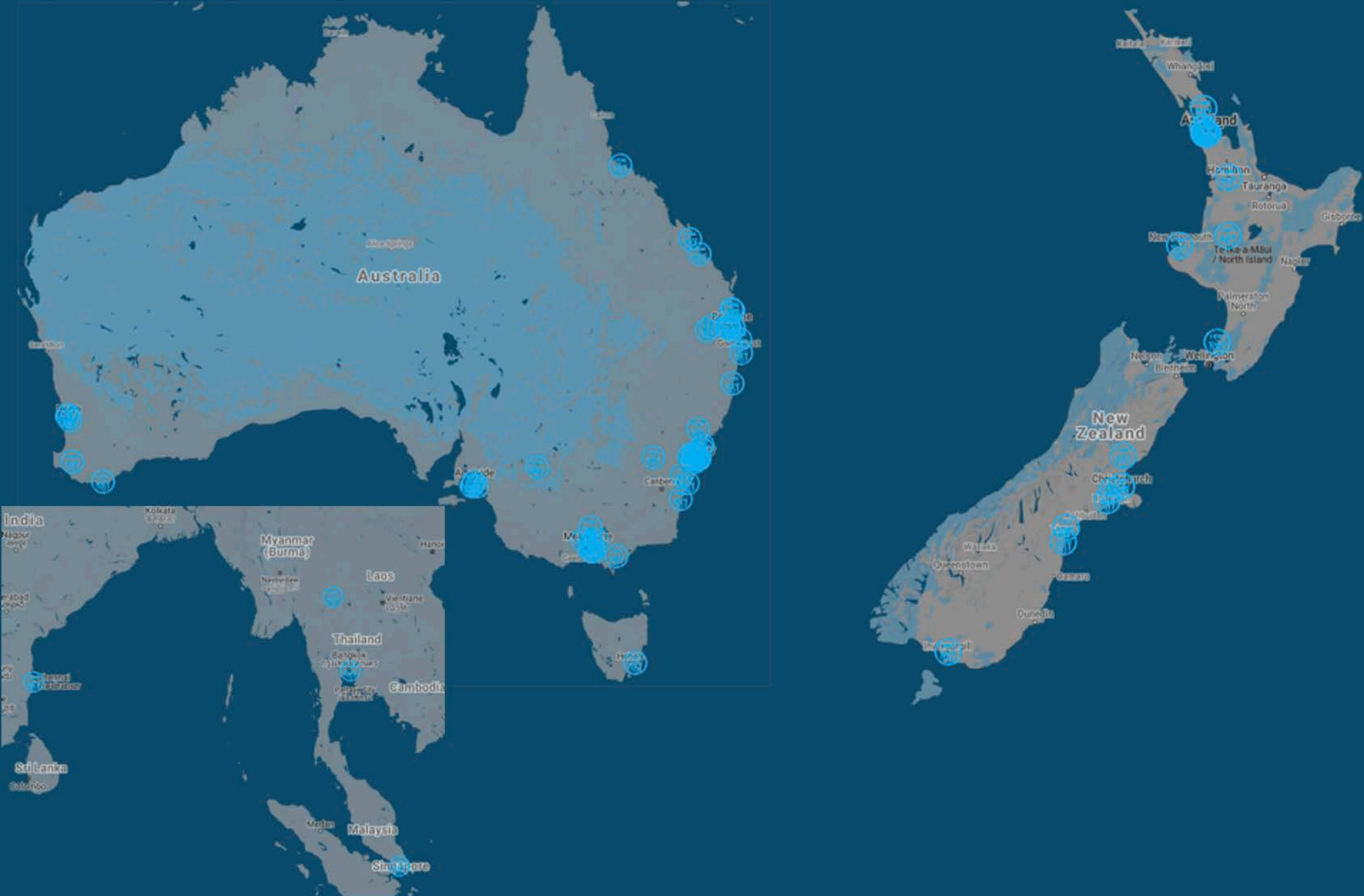


# OUR COMMUNITY ACROSS THE GLOBE

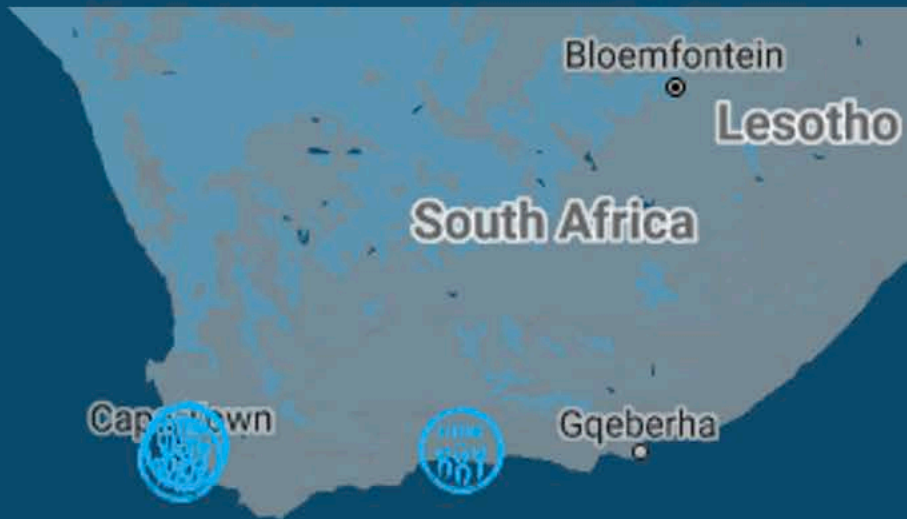
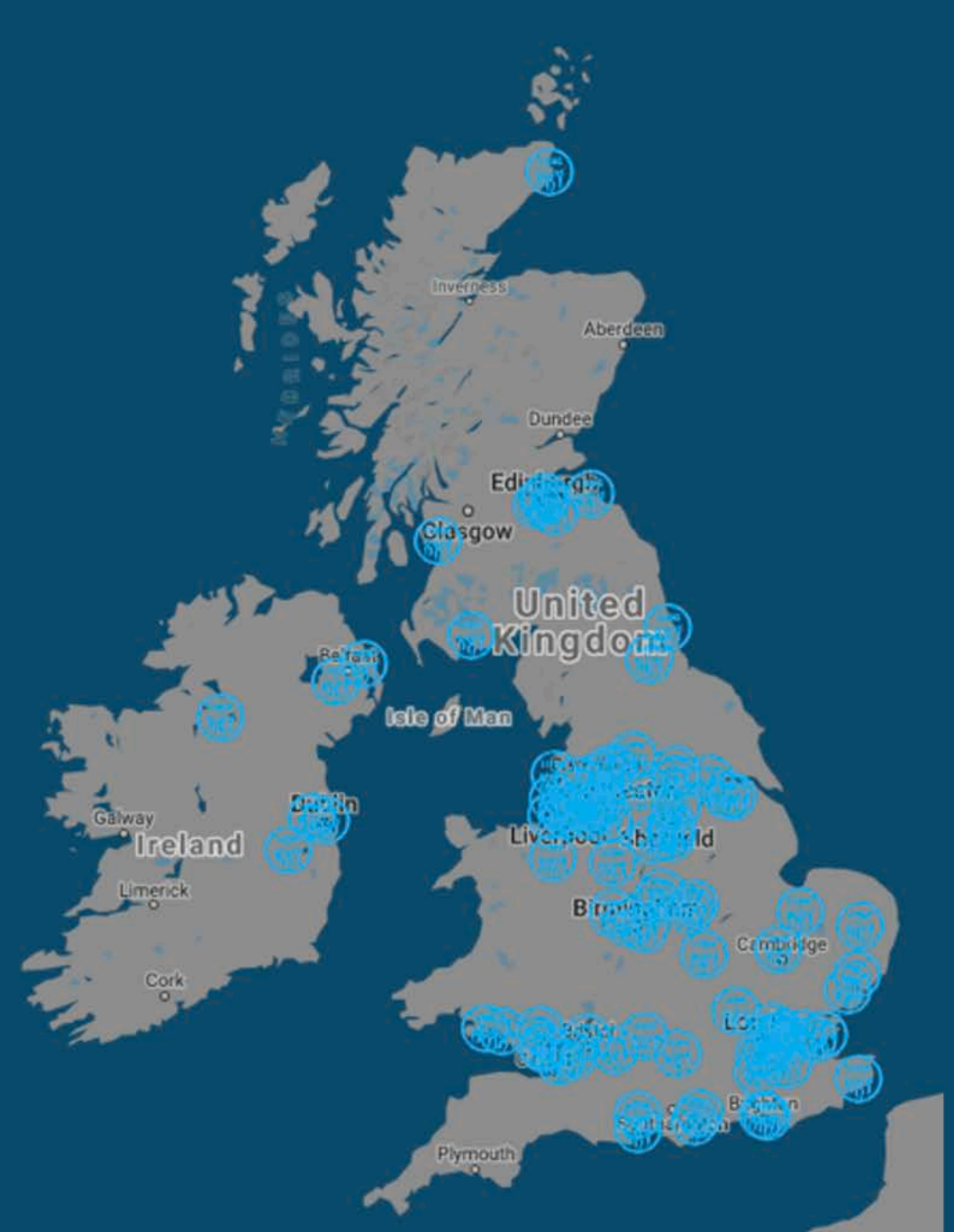
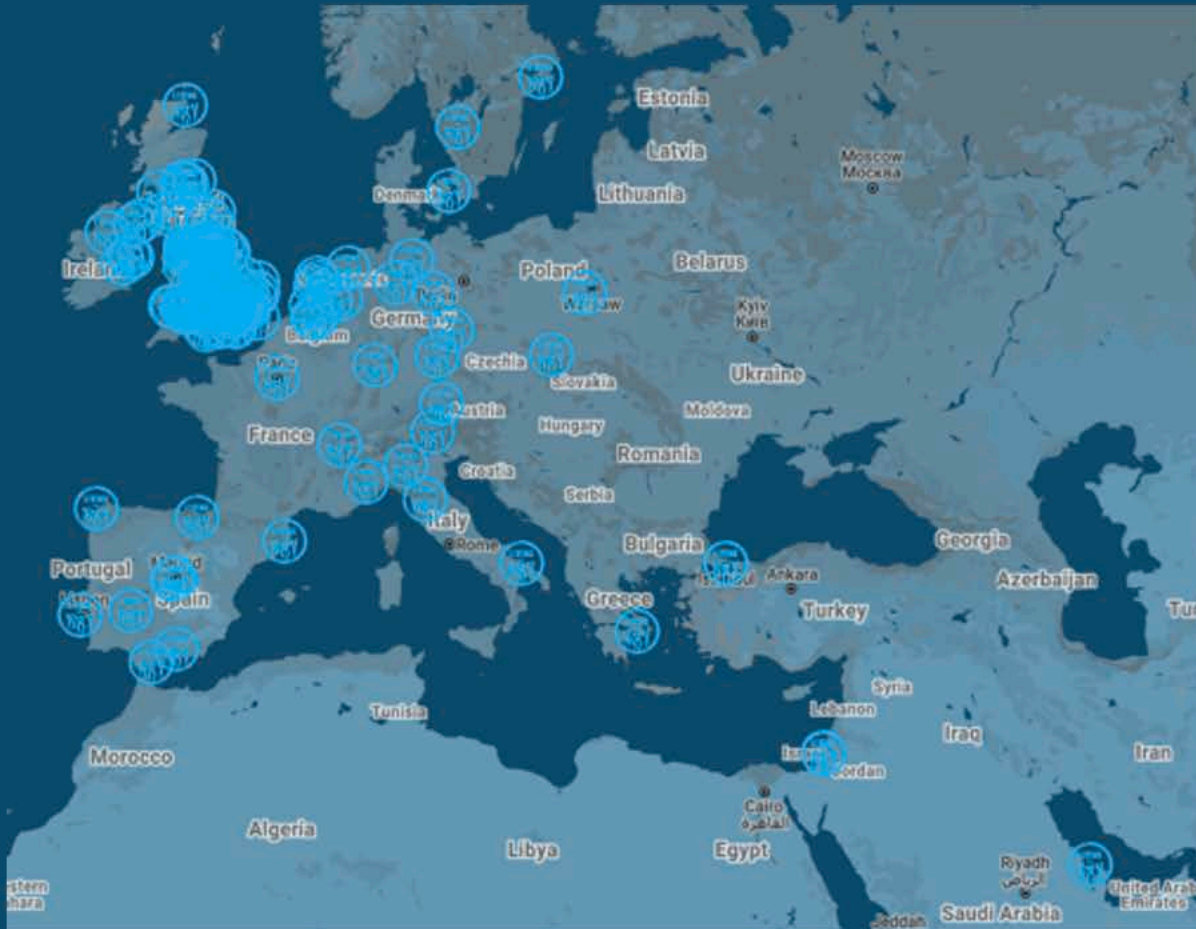
The maps you are about to look at were created by Ryan in the early days to connect people together and build community. Ryan mailed awareness cards and stickers, then connected people based off their location. This system is still being used today.



# AUSTRALIA, NEW ZEALAND, AND SOUTHEAST ASIA



# EUROPE, SOUTH AFRICA, AND THE UNITED KINGDOM



# OUR ADVOCATE PROGRAM



Connecting people of the community where they live so they can meet in person.

Offering independent support to those who feel they are not being heard.

Role models are important for developing a strong sense of self.

Representing Living With XXY in different countries around the world.

Sharing information beyond your diagnosis. Encouraging others to share their story.

# TRIBUTE TO OUR DONORS

Abeer Jassomah  
Adam Enterkin  
Aida Mazaheri  
Aimee Sanders  
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Karla Andrews  
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Kelsey Fuglsby  
Kendra Dill  
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Valerie Linteau  
Valeska Sbeghen  
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Vitor bragatto  
William & Linda Jones  
William Tatham  
York International

# FINANCIALS

Since the beginning of our nonprofit in November of 2019, Ryan Bregante and his board have been focused on being 100% Volunteer to get the nonprofit to a good place before Ryan was going to take a salary. We believe in being transparent to our community and showing where our donations go. Thank you for the support.

THE WAWONA TUNNEL

## Living with XXY

### Profit & Loss Report

October 2021

	TOTAL	
	OCT 2021	JAN - OCT, 2021 (YTD)
<b>Revenue</b>		
400 Contributions	2,474.62	50,562.11
420 Paypal/Stripe Contributions	479.30	15,029.29
430 Interest	0.70	7.09
450 Printful Sales	1,263.26	2,155.99
<b>Total Revenue</b>	<b>\$4,217.88</b>	<b>\$67,754.48</b>
<b>Cost of Goods Sold</b>		
140 Cost of Goods Sold	1,042.61	2,506.21
<b>Total Cost of Goods Sold</b>	<b>\$1,042.61</b>	<b>\$2,506.21</b>
<b>GROSS PROFIT</b>	<b>\$3,175.27</b>	<b>\$65,248.27</b>
<b>Expenditures</b>		
501 Utilities		35.30
502 Equipment Rental		255.31
504 Contractor		5,886.00
508 Office	123.70	2,105.66
510 Professional		2,450.00
511 Insurance		1,442.00
513 Taxes & Licenses		50.00
514 Supplies		106.68
516 Telephone	30.30	120.80
600 Advertising & Marketing		2,261.83
601 Meals & Entertainment		149.46
602 Dues & subscriptions	343.30	2,000.33
607 Legal & Professional Fees		400.00
608 Auto		50.31
610 Travel		2,073.91
620 Merchant Fees	28.75	879.60
<b>Total Expenditures</b>	<b>\$526.05</b>	<b>\$20,267.19</b>
<b>NET OPERATING REVENUE</b>	<b>\$2,649.22</b>	<b>\$44,981.08</b>
<b>NET REVENUE</b>	<b>\$2,649.22</b>	<b>\$44,981.08</b>

## WHAT'S AT STAKE?

As more pregnant mothers have access to early testing, such as NIPT (noninvasive prenatal testing), the numbers of Klinefelter syndrome diagnosis are increasing. Healthcare providers are pushing termination as the only option. It's critical that we continue to work on our mission, build accurate, up-to-date information and resources. Klinefelter syndrome is not a death sentence.

People who experience isolation, shame, or suffer from the stigma associated with Klinefelter syndrome are at increased risk for mental health issues. It's important for them to be supported during and after their diagnosis by their family, friends, and healthcare providers.

It's our job as a community to help raise the percentages of those diagnosed from 25% to 50% worldwide.

It's important to continue raising awareness so individuals living with Klinefelter syndrome can get the support they need. Advocating about male infertility, the importance of sharing accurate, updated information with those diagnosed, and focusing on changing the negative stigma surrounding 47, XXY is crucial. This will help those diagnosed live healthier, happier, and fulfilling lives. It will enable parents to make the best informed decisions when it comes to caring for their XXY baby and sons.

If we cannot reach our donation goals for each year, we will not be able to continue providing the crucial work our community needs.

SCAN TO DONATE



## FORWARD THINKING



LUKE GREEN AND RYAN BREGANTE

For 2022, we have some amazing projects planned for our community. We will continue to spread awareness and keep doing all the incredible things we are currently doing. We also plan to push our podcast to the next level and focus on in person support meet ups.

We have even bigger plans to go to the source of the misinformation and facilitate immediate, meaningful change. We will do this by working with providers to help them deliver diagnoses with more care and compassion, as well as provide patients with accurate resources and information.

Remember there is no reason why those with XXY can't live healthy, productive, and active lives. They can go to school, receive higher education, have careers, get married and have families. We will continue to save lives by working tirelessly to change the stigma surrounding Klinefelter syndrome/47, XXY.

We would like to thank our wonderful community and we are looking forward to many more years serving you. Thank you with plenty of love,

The Living with XXY Team