



OFFICIAL HOST TOOLKIT

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IN-PERSON EVENT INFO

- **A confirmed date, time, location**
- **A minimum of 50 attendees**
- **Registration required**
\$30 (includes t-shirt)
\$15 General Admission (no t-shirt)
- **Promo Code KAT6-** save \$5 per ticket when registering before August 1st.



Reimbursement for Event Expenses

Examples of expenses include park fees, food, drinks, ice, entertainment, paper/plastic. Hosts can be reimbursed up to 10% of their fundraising total. (Alcohol cannot be reimbursed).

KATwalk Banner

Each host will receive a **3ft x 6 ft** banner. Custom banners for hosts who obtain sponsorships. Sponsor **logos** must be sent to Aimee Reitzen at kat6aimee@gmail.com 3 weeks prior to your walk date.



KATwalk Team Leaders Facebook Group

Connect, ask questions, share ideas, and get real-time updates.

Team Social Media Graphic

Send a photo to Megan Stetts at mstetts22@gmail.com and she will create a graphic for you to use on Facebook, Instagram and more.



Spreadsheets

- The KATwalk team will provide each host with a spreadsheet with attendees and t-shirt sizes 3 days prior to walk.
- A final spreadsheet with donor contact info will be shared with team captains in early October after KATwalk is officially over.

Wristbands and stickers

FREE giveaways for registered walkers.



Host Rewards

Top teams will earn a \$100 voucher to KAT6 Foundation shop

KATWALK ANYWHERE INFO

Some of our top fundraisers each year are virtual fundraising teams!

Fundraise Online

No event planning necessary!
No walker registration fees!
Simply create a team fundraising page and share it on social media, email or by phone to solicit donations.

Team Social Media Graphic!

Send a photo to Megan Stetts at mstetts22@gmail.com and she will create a graphic for you to use on Facebook, Instagram and more.

New KATwalk Team

Leaders Facebook Group

Connect, ask questions, share ideas, and get real-time updates.

Order Tees for the Fam!

Show your unity with our KAT6 community by supporting our **Custom Ink t-shirt fundraiser.**

Wear your shirt throughout September and walk anywhere.



KATwalk Fundraising Materials

Visit <https://kat6a.org/fundraising-materials/> to download or print fundraising materials, sample emails, logos, brochures, signs and more.

Spreadsheets

A spreadsheet with your team's donor/contact information will be shared with each captain in early October after the KATwalk is officially over. You can use this to thank your supporters.

Host Rewards

Top Teams: \$100 voucher to KAT6 Foundation shop

HOW TO CREATE A KATWALK TEAM FUNDRAISING PAGE (powered by GofundmePRO)

Hog to Create a Fundraising Page:

View this [video tutorial](#) to walk you through the steps to creating a team page.

1. REGISTER on the KATwalk 2025 landing page at <https://donate.kat6a.org/KATwalk2025>

We recommend using a desktop or laptop computer to create your team, but your mobile device will also work.

2. Select "**Create a team**" and fill in the form. Be sure to include your address information so that we can mail you merchandise for your walk event.

3. Select Registration Type

KATwalk Team Captain Thanks for hosting a KATwalk event in your city! This registration is for team captains and their immediate household family members (Parents and siblings of KAT6 child). In-Person Hosts must select your t-shirt size.	Free - 0 +
KATwalk Anywhere This registration is for individuals and teams who cannot participate in a large KATwalk event in person. You can support our movement by casually walking in your own community and fundraising online.	Free - 0 +

4. Register each member of your family. After doing this, you will see a list of your family members. Next to your name, please click: "**Make Captain.**"

5. On the next screen you have the option to make a donation. You can do that or you may select "skip donation." And finish checking out.

6. Once you receive the "**Thank You!**" message, Your team is successfully registered.

7. Next to your team name choose "**View**" and you can edit the rest of your team page.

8. Go to the header of the page and select **SIGN IN** or **MANAGE** if you are already logged in.

If you had a KATwalk page in the past, you will need to use the same password, if you forget it then you will need to reset your password.

9. Select "GO to..."

In the dropdown, there will be a list of all your registered family members, **scroll to the bottom** and select your **TEAM PAGE**

Next, select **MANAGE** (if you are using a phone, this will be at the bottom right) From here you can add your **team photo, vanity link, and Edit Your Story**. Your story should include:

- Your walk details so that your participants know what to expect on the day of the event.
- Add photos, videos, and links with the tools at the bottom of the text block.
- Need inspiration? Share why this cause is important to you and its impact.

Need help? Try referencing this article: <https://support.classy.org/s/article/how-to-manage-your-team-as-a-team-captain> or contact the KATwalk team.

HOW TO SHARE YOUR FUNDRAISING PAGE

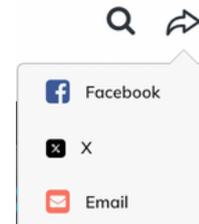
Mobile

1. Access your fundraising page
2. Select the menu icon at the top of your phone screen
3. Select Share this page
4. Choose to share your page through Facebook, Twitter, Email, or text



Desktop / Laptop

1. Access your fundraising page
2. Select the Share **arrow** at the top-right
3. Choose to share your page through Facebook, Twitter, or Email



How do I share on Instagram?

Since Instagram does not have the option to add hyperlinks to Instagram posts, we recommend adding a link to your fundraising page in the website section of your Account Bio or in an Instagram story. Here's an article to help you with this:

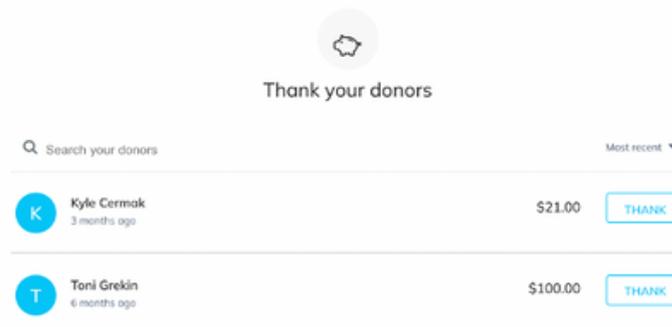
<https://embedsocial.com/blog/how-to-post-a-link-on-instagram/>

Email

There are some templates available to you in the email tab of Classy that you can use to encourage your teammates, ask for donations, or to thank your donors. Personalizing these emails will increase your fundraising success. Additional email samples are available at <https://kat6a.org/fundraising-materials/>

Give Thanks

Every time you login to classy, you can check the donations tab to see who has donated and you can thank them directly by clicking on the blue THANK button next to their name.



Invite Team Members to Help you Fundraise

We've found that email invites are one of the more effective and personal ways to recruit new team members.

Learn More: <https://support.classy.org/s/article/how-to-invite-team-members>

IMPORTANT INFORMATION FOR 2025 T-SHIRT ORDERS!



New Design This Year + Custom Tees for In-person Events!

Order deadline is August 15th to ensure on-time delivery for walk events.

Captains: We're excited to introduce **custom-designed t-shirts for participating walks who sell a minimum of 50 t-shirt tickets**. Don't worry, your walkers will still receive a general KATwalk shirt if you don't reach the order minimum. **Tees will be shipped to your home address and you will need to distribute them at your in-person event.**

As a thank you for hosting an in-person event, you will receive a t-shirt for each member of your immediate family (KAT6 parents/siblings)

Tell your walkers to purchase a KATwalk Admission with T-shirt.

They will select their size and walk location by August 15th.
T-shirts are unisex- available in youth, toddler and adult sizes.

Walking from ANYWHERE?

Your supporters can order a general KATwalk t-shirt via our Custom Ink fundraiser. Shirts are available in toddler, youth and adult sizes.

Click Here. Tees will be shipped **directly to each individual's home.**

 *International shipping is available — check Custom Ink for rates and details.*

For our **smallest walkers**, onesies can be purchased on our **KAT6 shop**.
(No order deadline)

COLLECTING DONATIONS

Share the website link

<https://donate.kat6a.org/KATwalk2025> and your specific team page link.

Scan this QR Code on your phone

Open your camera app and simply scan the code and it will direct you to the website donation page.



Encourage large donors to avoid credit card processing fees:

Mail a check

KAT6 Foundation
3 Louise Dr.
West Nyack, NY 10994

Send payment through Zelle

The Kat6a Foundation, Inc

Collect Cash

Any cash you collect can be converted into a check or you can submit it to the foundation via Zelle, Venmo or PayPal. This will be credited to your fundraising team.

@kat6foundation



venmo

Corporate Sponsors

Please reach out to Aimee Reitzen for additional support in securing corporate and small business sponsorship or gift giving.
Email: kat6aimee@gmail.com

MEDIA GUIDE

Contacting the media is optional.

Reaching out to your local media can be a great way to increase your fundraising efforts and to raise awareness about KAT6 syndromes. It's not as difficult as it sounds.

- Look up your local newspaper/tv media outlets online. Usually they have a contact form on their website that you can fill in. There may also be an email address and phone number provided. You have an interesting story to tell, and your local news wants to share it!
- Prepare yourself for a Zoom or in-person interview. First jot down some notes about what you are comfortable sharing about your personal journey. Next, use some of these talking points below to help drive home the importance of the KATwalk.

FACTS ABOUT KAT6 SYNDROMES

- Approximately 700 individuals have been diagnosed with KAT6 syndromes internationally.
- Most individuals are diagnosed through genetic testing.
- The most common features are: global developmental delay, significant speech and language deficits, feeding difficulties, distinct facial features, gastrointestinal issues, intellectual disability, vision issues, abnormal muscle tone, heart defects and sleep disturbances. (See Infographic p. 14)

FACTS ABOUT THE FOUNDATION

- The Foundation created the KAT6A/KAT6B Patient Registry in collaboration with the National Organization of Rare Diseases (NORD). Today, over 500 individuals are registered. This is the largest collection of KAT6 patient data.
- In 2025, The Foundation approved funding for 7 new research projects! We are currently funding 13 in total! Visit <https://kat6a.org/funded-projects/> to learn about them.
- The Foundation provides Empowered Grants to support families that require specialized equipment and therapies to assist their child's development. We have given over 120 grants since the effort began in 2020.
- The Foundation created its first biobank in June 2022. KAT6 cells are stored at the Center for Regenerative Medicine at Boston University.

WHY SUPPORT THE KATWALK?

- BUILD a stronger support network for people with KAT6 syndromes and their families by assisting caregivers when they need help the most through support groups, webinars and conferences.
- EMPOWER families by providing grants for assistive equipment, technology and therapies.
- SUPPORT individuals diagnosed with KAT6 syndromes by funding groundbreaking research that could lead to a treatment.
- EDUCATE health care professionals to improve quality of patient care, accelerate diagnoses through genetic testing, and expand our KAT6 medical network.
- EXPAND knowledge of the entire genome. KAT6 research is applicable across many patient populations. The possibilities are endless!

SAMPLE EMAIL



Dear Family and Friends,

I'm reaching out to ask for your help with something very close to our hearts. As many of you know, our child has been diagnosed with an ultra-rare genetic disorder called KAT6. It's a journey that has brought challenges, but also hope—thanks in large part to the incredible support we receive from the **KAT6 Foundation**. This organization has become a lifeline for our family, providing emotional support, healthcare resources, research connections, and a community that truly understands.

Every September, the Foundation hosts its biggest annual fundraiser and awareness event: the KATwalk. This year, **the goal is to raise \$175,000**, and we would be so grateful if you could help us reach it. You can donate directly to my **team** *[insert team page link!]*.

Your contribution—no matter the size—will make a real difference by supporting:

- Empowered Grants that help families like ours afford essential therapies and assistive equipment
- The KAT6A & KAT6B Patient Registry, which connects families and shares vital medical data with researchers around the world
- Innovative research into biomarkers and potential therapies- laying critical groundwork for clinical trials.
- The annual KAT6 Conference, where families, doctors, and scientists come together to share knowledge and build community

If the fundraising goal isn't met, some of these crucial programs may be reduced—a heartbreaking setback for a rare community that depends on them.

You can learn more about the Foundation and the amazing work they're doing at www.kat6.org.

Thank you for your continued love, generosity, and support. It truly means the world to us.

With love,
[Your Name]

[See more samples here](#)
[and download/edit](#)

walking for a brighter tomorrow



KATwalk

JOIN US

Date:

Time:

Location:

Contact:



WHAT IS THE KATWALK?

THIS FUNDRAISING EVENT IS SPONSORED BY THE KAT6 FOUNDATION, A 501(c)(3) NONPROFIT ORGANIZATION. THE KATWALK TAKES PLACE EACH SEPTEMBER TO RAISE MONEY TO SUPPORT CHILDREN LIVING WITH KAT6 SYNDROME. THIS ULTRA RARE DISEASE SEVERELY IMPACTS THE HEALTH AND DEVELOPMENT OF CHILDREN DIAGNOSED.

GIVE NOW

DONATE.KAT6A.ORG/KATWALK2025

EVENT DAY REMINDERS

On the day of your walk remember to bring:

1. KATwalk banner (and string to hang it)
2. Wrist Bands
3. Stickers
4. Registration Spreadsheet (check your email)
5. Pens, scissors, tape
6. Coloring page & crayons (optional)
7. Print/Display QR code flyer (page 12 in toolkit) or create your own!
8. Bring t-shirts to distribute to walkers who chose to pick up at your event.

Tips to help make your day go smoothly:

- Send a reminder email to your attendees a few days before your event.
- Designate a helper for you at your check-in table to distribute tees and handle any last minute registrations
- Hang your banner in a visible spot in order to raise awareness.
- Share some words of appreciation to your supporters and let them know how the foundation uses their donations. *See page 8 for talking points about KAT6 syndromes and work being done at the Foundation.*
- Keep any cash/checks you collect at your walk in a safe place. Registration is \$15 per person for same day registration (no tee). They can give you cash or register using their mobile devices.
- We will ship you a few extra tees to sell at the walk, but they will be limited (\$15 each plus \$15 registration if they haven't already paid).
- Taking photos can be difficult to do when you are hosting. We recommend that you designate a friend or family member to circulate and take photos/videos.
- Encourage your attendees to post on social media using #KATWALK2025. Ask them to tag KAT6 Foundation. We are on Instagram, Twitter and Facebook.
- Save your receipts for host reimbursement.

HAVE FUN!!



Thank you for joining us today!



GIVE NOW

We are so grateful for your participation and support this year! It's not too late to support our team. Simply scan the QR code and select register and join our team!

Help us raise awareness!

Share photos from today on social media.
Use #KATwalk2025



**WALKING FOR
A BRIGHTER
tomorrow!**



DOWNLOADS

Download these materials at KAT6A.ORG/FUNDRAISING-MATERIALS/

24 X 36 IN INFOGRAPHIC

SOCIAL MEDIA FRAME

UNDERSTANDING KAT6 SYNDROME

Mutations in **KAT6A** and **KAT6B** genes can lead to a neurodevelopmental disorder.

KAT6A AKA: Arboleda-Tham syndrome, Lysine (K) acetyltransferase 6 A, MOZ, MYST3

KAT6B AKA: Genitopatellar syndrome (GPS), lysine acetyltransferase 6B, MORF, MYST4, Ohdo syndrome, Say-Barber-Biesecker-Young-Simpson (SBBYS)

COMMON SYMPTOMS

- feeding difficulty
- GI issues
- intellectual disability
- motor/movement disorder
- ADHD
- autism
- sleep disturbance
- hypotonia
- vision issues
- craniofacial dysmorphism
- cardiac malformation

DIAGNOSING KAT6

Ask your medical team about **Whole Exome Sequencing** and the **Intellectual Disability NGS Panel**. Both tests can identify KAT6 mutations.

700

Today, approximately **700** individuals have been diagnosed with KAT6 around the world.

ULTRA RARE

A disease is considered rare if it affects fewer than **1 in 2,000** people.

LESSER KNOWN SYMPTOMS

- hearing loss
- CVI
- dental anomalies
- respiratory problems
- renal/urogenital abnormalities
- behavioral problems
- chiarì
- epilepsy
- growth delay

SPEECH DELAY is the most common feature — ranging from mild to severe.

YOU CAN ACCELERATE TREATMENTS FOR KAT6 BY SIGNING UP TO PARTICIPATE IN RESEARCH AND JOINING OUR PATIENT REGISTRY.

GASTROINTESTINAL COMPLICATIONS

Although uncommon, the leading cause of death in KAT6 is **intestinal blockage**. This is a medical emergency — never ignore signs of abdominal pain, vomiting, or severe constipation.

Most KAT6 variants are **DE NOVO** meaning they aren't inherited.

2017

KAT6 Foundation was established in **2017**. We support the international KAT6 community.

THROUGH EVERY RESEARCH STUDY AND EVERY DONATION, WE'RE BUILDING A BRIGHTER, STRONGER FUTURE FOR KAT6 FAMILIES — **TOGETHER**

KAT6 Foundation

LEARN MORE AT KAT6.ORG

walking for a brighter tomorrow **2025**

KATwalk
KAT6.ORG

Email Megan Stetts a photo and she'll create a customized graphic for your social media posts and stories.
Email: mstetts22@gmail.com

KAT6 LOGOS



SAMPLE FUNDRAISING LETTERS

Choose from a selection of fundraising letters to customize by copy/paste to your personal email to solicit donors and walkers. [Click here.](#)

HOST REIMBURSEMENT FORM

Host Name _____
Phone _____
Email _____
Event _____
Mailing Address _____

Item	Description	Cost

Total _____

****Submit this form to Emile Najm at kat6a@yahoo.com. Make sure to attach your receipts in the email.**

Indicate your Reimbursement Method: PayPal, Zelle or personal check

Provide your PayPal account email address or mailing address for a check if it is different than the information listed above.

(signature)

(date)

*Official walk hosts will be reimbursed for their out of pocket expenses. Examples of expenses may include park fees, food & drinks, entertainment, etc.
Hosts will be reimbursed up to 10% of their fundraising total.*