



**Kennedy's
Disease
Association**

Strength In Every Stride

**Every Step
Brings Us
Closer to
a Cure**

**100
STEP
CHALLENGE**

TEMPLATES

Thank You For Joining Us In Taking Meaningful Steps For Kennedy's Disease

Together, we're making strides in raising awareness, securing research funding, and strengthening our community.

The 100-Step Challenge is a movement built on hope, strength, and unity. Whether you take your steps alone, with family, or as part of a team, know that each step is a powerful statement of support.

We are so grateful to have you as part of this journey.



Let's take this journey together and make an impact that lasts far beyond the challenge!

John's Journey

John who issued the first 100-Step Challenge posted the following on his Condo Association's Facebook page:

Some of you know me as the Directory Guy, others may think of me as Scooter Man. However you think of me, I am also a guy with Kennedy's Disease.

In 2005 I was diagnosed with KD. I have been fortunate and continue to function well with the help of my trusty Hurrycane, Nitro Rollator and Scooter.

Since it is genetic, I received the gene mutation from my mother and unfortunately, I may be passing it on to future generations of my family. That is why I am passionate about finding a cure.

Last year, my 100-Step Challenge fundraising campaign raised \$35,000, but we need to do more. I can't do it alone. Will you join me in the fight against Kennedy's Disease? John L.



What is Kennedy's Disease?

Kennedy's Disease (KD) is an X-linked genetic neuromuscular disease that causes muscle weakness and atrophy throughout the body. While both men and women can carry the gene, symptoms primarily affect men, usually between ages 30 and 50. Over time, many individuals with KD require mobility assistance, and by their 50s, some may become wheelchair-bound. Once considered very rare, recent studies suggest that more people may have KD than previously thought.

Kennedy's Disease Goes By Many Names



June is Kennedy's Disease Awareness Month!

June is a meaningful month, as we celebrate Kennedy's Disease Awareness Month and Father's Day - a day when we honor fathers, sons, brothers, uncles, and grandfathers.



Our Mission

The Kennedy's Disease Association's Mission is to inform, support, educate, fund research, and find a treatment and cure for Kennedy's Disease. To learn more, visit: www.kennedysdisease.org

About the Kennedy's Disease Association

Kennedy's Disease Association (KDA) is an all-volunteer 501(c)(3) non-profit organization, dedicated to finding a cure for KD. Since its inception, KDA has contributed over \$2.5 million to global researchers through a competitive grants program funded by donations from our patients, their families and friends. KDA provides a support network for men with Kennedy's Disease, as well as for carriers and caregivers. KDA works to increase awareness of the disease among health professionals and the general public. KDA sponsors an annual conference to bring patients, researchers, and clinicians together to share information and learn about developments in the search for a cure for Kennedy's Disease.

The Most Meaningful Walk of My Life

Steps I Will Always Remember

On my wedding day, my dad walked me down the aisle - a moment I wasn't sure would be possible. He was struggling to stay on his feet due to what we didn't know was Kennedy's Disease.

On that day, with a cane in one hand and me supporting him on the other, he walked those precious steps, smiling proudly beside me.

I held him steady as we moved down the aisle, step by step. Tears welled in my eyes from gratitude that he could be there with me.

It took seven years to receive a diagnosis: Kennedy's Disease, yet he never once complained about his condition. He found joy in simple things, like riding his John Deere mower around the yard. I cherish that memory. He couldn't walk much anymore so it gave him a sense of freedom. That was his way of holding onto dignity, independence and happiness.

This is why I'm passionate about finding a cure for Kennedy's Disease. Every step you take, and every dollar you donate helps people like my dad. It's not just about a cure - it's about giving families the support they need for those simple, everyday moments that matter the most.

Carol Frey Clark



Ron Frey and Carol Frey Clark
October 24, 1998

Why 100 Steps?

For many men living with Kennedy's Disease, walking just 100 steps without assistance is a significant challenge.

The 100-Step Challenge represents their daily struggles, strength and perseverance.



Small movements can be challenging



Getting around is not easy



With the right support and awareness, we can help create a world where no one has to face this journey alone.



Daily tasks are a struggle without help



Chewing and swallowing can be difficult

Every step taken raises awareness, helps fund critical research, and is a reminder that every contribution matters.

Daily Life Can Be a Daily Battle

Kennedy's Disease often begins with subtle symptoms like muscle cramps, fatigue, and limb weakness. As the disease progresses, muscle deterioration can make everyday tasks like walking, climbing stairs, or carrying groceries increasingly difficult. Many eventually rely on mobility aids. Some also experience difficulties with chewing, swallowing, and speaking, further impacting their quality of life.



The Hidden Burden of Being a Carrier

Imagine learning that you carry a gene that gives your sons a 50% chance of developing a debilitating disease, and your daughters a 50% chance of passing it on. That's the harsh reality for female carriers of Kennedy's Disease. While carriers may remain symptom-free, the emotional burden of potentially passing it to future generations is profound.

Hope Starts With a Single Step

As you take your next 100 steps, think about what it would be like to slowly lose the ability to walk those steps. Imagine knowing that you could pass this disease on to your children and grandchildren. This is why we are passionate about finding a cure.



The 100-Step Challenge is a powerful way to take action. Each step raises awareness, each donation fuels research, and each participant stands in unity with those affected.

Together, we can walk toward a future filled with hope, and one day, a cure.

WHAT is the 100-Step Challenge?



Many men affected by Kennedy's Disease can't walk 100 steps without assistance.

The 100-Step Challenge is an impactful way to raise awareness and funds for Kennedy's Disease.

Whether you take 100 steps, roll 100 feet, or complete 100 movements in your own way, your participation helps shine a light on those living with Kennedy's Disease and brings us one step closer to a cure.

WHO Can Participate?

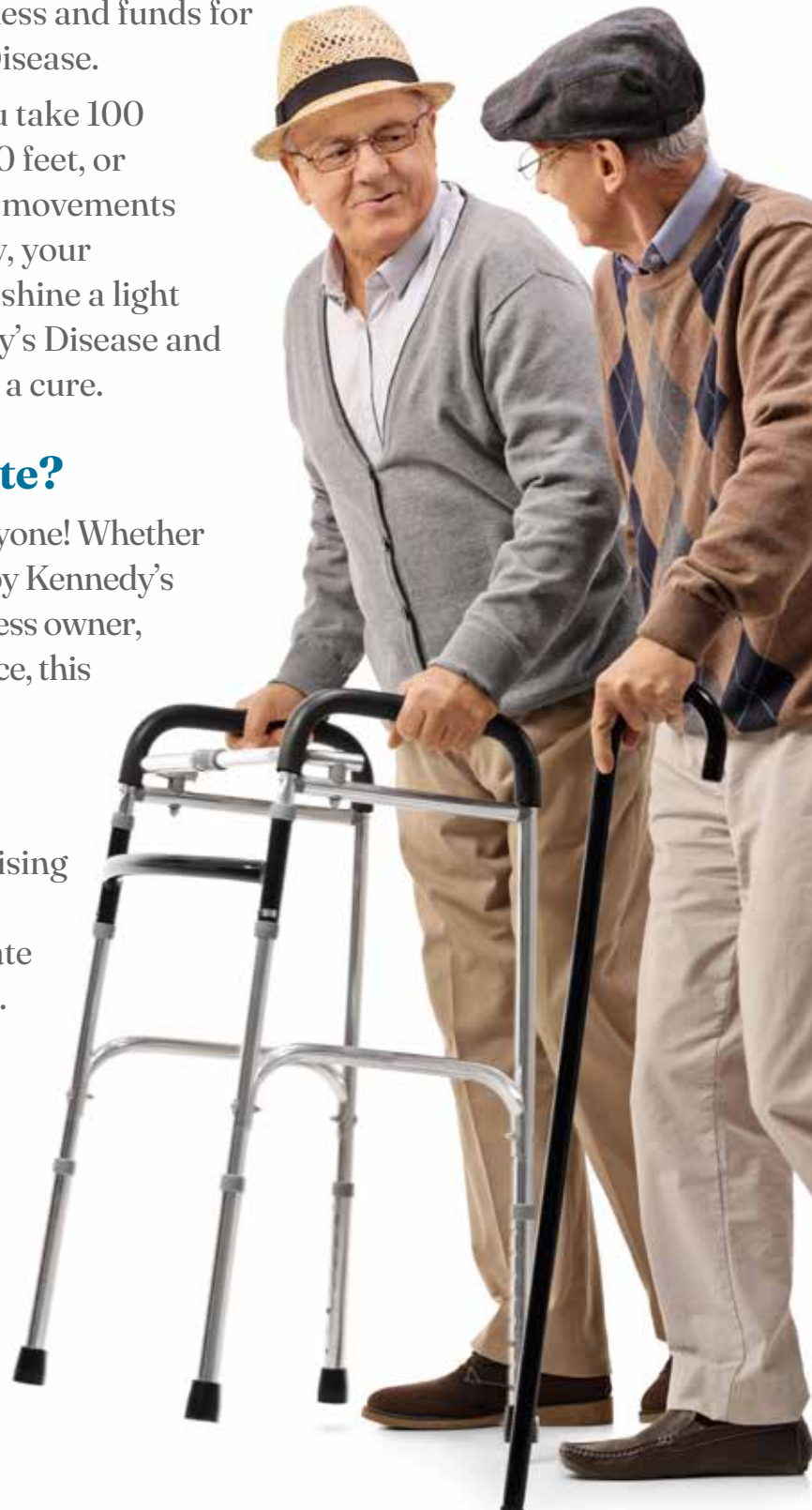
This challenge is open to everyone! Whether you or a loved one is affected by Kennedy's Disease, you're a supporter, an athlete, a business owner, or just someone who wants to make a difference, this challenge is for you!

WHEN – NOW

The 100-Step Challenge is an annual fundraising event held throughout the month of June, however individuals may choose to participate by fundraising any time throughout the year. June is a meaningful month, as we celebrate Kennedy's Disease Awareness Month and Father's Day - a day when we honor fathers, sons, brothers, uncles, and grandfathers.

WHERE – ANYWHERE

Fundraising for the 100-Step Challenge happens anywhere around the world!



HOW the 100-Step Challenge Works



Help us reach our goal of raising \$200,000 to fund critical research and help change the lives of those impacted by Kennedy's Disease and for future generations.

Getting Started

1

Sign Up & Create Your Personalized Fundraising Page

REGISTER

Visit our official website to register and set up your personalized fundraising page. It only takes a few minutes to get started!

2

Get Moving & Start Your Challenge

Commit to completing your 100 steps (or equivalent activity) each day - or create your own unique challenge! Record your daily progress in a notepad or using our easy-to-use tracker.



DOWNLOAD

100-Step Challenge Tracker

3

Share Your Story & Raise Funds

Share your personal journey to help others understand the impact of Kennedy's Disease and the importance of this challenge.

Consider writing a heartfelt message to family and friends, and invite them to support your mission – by joining the challenge or making a donation to the Kennedy's Disease Association.

Show your appreciation by saying Please and Thank You!



DOWNLOAD

Sample Letters, Emails & Messages

Not ready to participate but still want to support?

DONATE

Let's take 100 steps
for Kennedy's Disease
together!

Participate Your Own Way!



Choose the approach that aligns best with your comfort level and resources, and know that your efforts are deeply appreciated.

Engage a Wider Community

Remember, every step you take and every person you engage brings us closer to understanding, supporting, and ultimately finding a cure for Kennedy's Disease.



Check out our important communication materials, including our easy-to-use downloadable resources and digital content.

IMPORTANT LINKS



100-Step Challenge Website



My Fundraising Page Login



Resources



FAQs

DOWNLOADS



100-Step Challenge Toolkit



100-Step Challenge Tracker



Templates - Sample Letters & Messages



Fundraising Tips

DIGITAL CONTENT



Pledge Card



Email Signature



Virtual Background

Every step counts. Join us in taking 100 steps toward hope, awareness, and a cure for Kennedy's Disease.

Set Up and Personalize Your Fundraising page!

Most potential donors will be people you personally know - friends, relatives, co-workers, and others within your social network. Often their decision to donate is because they are supporting you. For this reason, inspiring your supporters is key to your success. You need to explain why you have chosen to participate, what the KDA means to you, and how their contribution can help the KDA achieve its goals.

Share Your Story

Share your personal journey to help others understand the impact of Kennedy's Disease and the importance of this challenge.

Share Your Page

People can't say yes to donate if you don't ask them. An easy way to ask is by sharing your page – just click the “Share” button on your fundraising page

Share Your Progress

Let people know about your fundraiser and how you're progressing on Social Media if you wish, using pictures, videos, or just posting an update.

Use our hashtags: #KDA100StepChallenge, #KDA100Steps, #100Steps4KD, #StrengthInEveryStride #KennedysDisease #KDAwareness #100StepChallenge

Donate to Your Own Page

By donating even a small amount to your Fundraiser, people see that you really care about what you're doing and it will encourage others to do the same!

Thank Your Supporters!

Remember to thank your friends, family and everyone who has donated to you. When you get a notification on your fundraising page that someone has donated, be sure to comment and say thank you!

Did you know?

90% of every dollar raised goes directly toward funding critical research.

Bay Area Rare Disease Day

The 7th Annual Rare Disease Day Bay Area event brought powerful stories, live performances, and an outpouring of community support in San Jose's Japantown. The event raised over \$9,000 for the Kennedy's Disease Association, supporting research and giving hope to those affected by rare neuromuscular disorders.

DimSum Give Some: A Taste of Hope

Led by Top Chef finalist Dan Jacobs, Dim Sum Give Some has raised over \$150,000 since 2017 to support Kennedy's Disease research—proving the power of food and community in the fight for a cure.



13th Annual KD Golf Scramble



Thanks to events like the 13th Annual KD Golf Scramble, real progress is being made in the fight against Kennedy's Disease. Over the past 13 years, this incredible tournament has raised more than \$343,000 to support critical research, raise awareness, and bring hope to families affected by this rare neuromuscular disorder. This year's event continued that tradition by generating vital funds to accelerate progress, expand outreach within the scientific community, and remind everyone touched by Kennedy's Disease that they are not alone, and that a cure is within reach.

Sample Letter & Email

I'm excited to announce that I am supporting the Kennedy's Disease Association, and today I'm launching my personal fundraising campaign [add direct link to your page].

I'm asking my family members, friends, and neighbors to help me reach my goal of [\$XXX] and support the KDA's efforts to fund critical research to find a cure for Kennedy's Disease.

A gift to the KDA helps to create a hopeful path forward.

Would you join me today by donating [\$XX]? It will mean so much to me! :-)

Click here to learn more and donate on my page [add direct link to your page].

Thanks for your consideration,

[Your name]

Sample Thank You Note

Hi, [Friend's name]!

Thank you so much for supporting me and my fundraiser to fight KD. Because of you, I was able to raise [\$XXX] for the KDA!

Together, we are making a difference in the lives of those impacted by KD by funding critical research, education, awareness, and support for patients and their families.

You rock!

Thanks for your support,

[Your name]

Sample Cut & Paste Messages

I received notice that you will be sending a donation to the Kennedy's Disease Association. Thanks so much. I really appreciate it. We will watch for it and circle back when it is received.

* * *

Thanks so much for your generous donation to the Kennedy's Disease Association. I am passionate about doing what I can to help find a cure or treatment before it impacts our grandkids. Your donation brings us one step closer. It is truly appreciated.

* * *

Thanks so much for your generous donation. I really appreciate it. It is about finding a cure or treatment for future generations.

* * *

Circling back to let you know that your check has been received. Thanks so much for your generous donation to the Kennedy's Disease Association. I am passionate about doing what I can to help find a cure or treatment before it impacts our grandkids. Your donation brings us one step closer. It is truly appreciated.

* * *

A brief update to let you know, in our first week, over [\$ AMOUNT] has been donated towards our Goal of [\$ AMOUNT]. All money donated will go to the Kennedy's Disease Association to fund research in search of a cure. Kennedy's Disease affects me and thousands around the world. It does not discriminate. I hope I can count on you to help close the gap. Every donation moves us one step closer to a cure. Please click here to learn more and donate to the Kennedy's Disease Association 100 Step Challenge. Your support is truly appreciated.

* * *

A brief update to let you know we are over halfway to our aggressive fundraising goal. I am overwhelmed by the generosity of my network of friends and family. All money donated will go to the Kennedy's Disease Association to fund research in search of a cure. Kennedy's Disease affects me and thousands around the world. I hope I can count on you to help as we push towards the goal. Every donation moves us one step closer to a cure. Please donate to the Kennedy's Disease Association 100 Step Challenge. Your support is truly appreciated.

* * *

A brief update to let you know, we are making steady progress towards our fundraising goal for the Kennedy's Disease Association. I am overwhelmed by the generosity of my network of friends and family. Every donation moves us one step closer to a cure. Please donate to the Kennedy's Disease Association 100 Step Challenge. Your support is truly appreciated.

Sample Social Media Post

Join the 100-Step Challenge for Kennedy's Disease Awareness!

Every step matters—whether you walk, roll, or support from the sidelines. The 100-Step Challenge is a simple, inclusive way to raise awareness for Kennedy's Disease and show support for those affected.

How It Works:

- Take 100 steps (or whatever feels right for you)
- Do it anytime, anywhere—privately or with friends
- Share a photo or story (optional!) to help spread awareness

Tag #100StepChallenge #KennedysDisease if you'd like to participate online.

This challenge is about unity and awareness, with no pressure to share publicly. If you'd like to learn more or participate privately, visit <https://secure.qgiv.com/event/kda-100-steps/>.

Every step counts! Who's in?

100-Step Challenge Tracker



June 2025

Complete your steps and record your progress on your calendar.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					

Do you have questions about the fundraiser?

Visit the [100-Step Challenge FAQs](#).

How can my supporters donate?

Your supporters can donate in 4 ways:

1. Online donations are made directly from within your Fundraising page.
2. Donate by mail by sending a check.
3. Donate through a Donor Advised Fund (DAF).
4. Tax free donation from their annual Required Minimum Distribution (RMD) by using a Qualified Charitable Distribution (QCD)

Donate by Mailing a Check:

Kennedy's Disease Association
1445 Woodmont Lane NW #1805
Atlanta, GA 30318

Donate from a Donor Advised Fund

EIN: 77-0552005
Phone: (855) 532-7762
Kennedy's Disease Association
P.O. Box 1105
Coarsegold, CA 93614

Donate Directly from Your RMD

Donate Directly from Your RMD through use of a Qualified Charitable Distribution (Special IRS Rules Apply). See your Financial Advisor or Retirement Plan Custodian.
Kennedy's Disease Association
1445 Woodmont Lane NW #1805
Atlanta, GA 30318

Have more questions?

We're here to help you succeed! Please email us at info@kennedysdisease.org for help with your fundraising efforts.

Thank You!



Thank you for supporting the Kennedy's Disease Association!

YOU are a part of something BIG, and your efforts make a BIG impact!

Stay in Touch!

Kennedy's Disease Association

1445 Woodmont Lane NW #1805

Atlanta, GA 30318



Phone: (855) 532-7762



Outside US: (734) 288-5580



Email: info@kennedysdisease.org





100 STEP CHALLENGE



**Kennedy's
Disease
Association**

1445 Woodmont Lane NW #1805 • Atlanta, GA 30318

Phone: (855) 532-7762 • Outside US: (734) 288-5580 • Email: info@kennedysdisease.org