I CAN MOVEment | June 23-29, 2024

FACT SHEET

I CAN MOVEment is Cure VCP Disease's annual fundraising campaign. It is a virtual move-a-thon, where those participating pick a personal movement challenge. Any movement is fair game, whether walking, cycling, swimming, wheelchair distance, finger raises, stretches or more! Throughout the week of June 23-29th, participants will work towards their goal, sharing their personal progress and their story.

Donations support scientific research and patient programs to advance care for patients and families suffering from VCP disease.

Many patients with VCP disease have myopathy, a form of muscle weakness that can lead to decreased mobility, decreased physical activity, and other health issues. That's why our move-a-thon lets each participant pick a movement activity of their choice to participate in, right in their own community, anywhere in the world. Perhaps some want to walk 5k throughout the week, others may want to exercise in the pool every day, and some others may choose to lift household items or take wheelchair laps.

How to participate in the **I Can MOVEment**

- **Pick a challenge**: what movement goal speaks to you? Think about an activity that you would like to achieve over the course of a week
- **Sign up**: Go to 2024 I CAN MOVEment (givebutter.com) and click the "Sign-up" button. You can upload a profile picture, share about your selected challenge and more
- **Share your why to fundraise and encourage others to participate**: Let your friends and family know about your role in the I Can MOVEment by sharing the link your page on social media and sending e-mails. In your e-mail, request donations of support and encourage others to participate by picking their own challenge. Sharing your story raises awareness about VCP disease
- **Participate in challenge week and celebrate!:** During challenge week, enjoy your work to achieve the goal you set. Take photos, videos and share your progress with your community and with Cure VCP disease. After the week, share your success, update your fundraising contacts to thank your donors and let them know about your achievement!

Why participate? VCP disease is an ultra-rare, debilitating genetic disease that affects patient's brain, muscles, bones and nerves. Funds raised during the I CAN MOVEment will go towards patient support programs and important scientific research to work towards a treatment and cure.

Want more info? Read our FAQ or e-mail info@curevcp.org

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Frequently Asked Questions:

What is a virtual move-a-thon?

It's like a walk-a-thon but each participant picks a movement activity of their choice (run, swim, dance, wheel-chair laps, anything). All the tools to participate and fundraise are online, so participants can create a fundraising page, advertise it, and ask for pledges or donations all over the world.

What are the dates?

We picked the week of June 23-29, so your personal challenge can be over several days or just one day. If that date does not work out for you, that's OK! Pick dates that work for you, contact info@curevcp.org and we can share updated fundraising materials with you.

Who can participate?

Anyone and everyone.

How do I join?

Go to 2024 I CAN MOVEment (givebutter.com) and click the "Sign-up" button. You can upload a profile picture, details of your movement challenge, and your story.

For detailed instructions to set-up a page, click here: How to manage your Team Member page | Givebutter Help Center or e-mail us @ info@curevcp.org

How do I give?

Click the "Donate" button on 2024 I CAN MOVEment (givebutter.com)

Can people pay by check or cash?

Yes. Make checks out to Cure VCP Disease and mail to 1302 Watson Blvd #1015, Warner Robins, GA 31093. Let us know if you are mailing donations so that we can track it. allison@curevcp.org

Who is Cure VCP Disease?

We are a non-profit organization dedicated to finding a cure for VCP disease, a genetic, debilitating, rare disease. There are no cures or treatments for this fatal disease. The organization was founded six years ago by a group of determined patients, and we have made tremendous strides … funding over $400,000 in research, organizing a scientific conference, hosting an annual patient conference, and facilitating a global research network. Most importantly, we have fostered a supportive patient community who support each other and are fighting for a cure. Finding a cure is in our DNA.

Social Media

The key to a successful fundraiser is getting the word out and telling your story. Below are a few ideas for social media posts. Feel free to put your personal touch on each one. Be sure to include the donation link on each message.

SAMPLE MEDIA POST TO RECRUIT PARTICIPANTS:

Let’s join the movement to CURE VCP DISEASE together. I’m launching a team to raise awareness and funds to find a cure my rare disease. During the week of June 23rd, I am going to challenge myself to ________ . Will you join in? What’s your personal challenge? It’s easy and fun! Let’s cure VCP disease together. 2024 I CAN MOVEment (givebutter.com)

SAMPLE MEDIA POST FOR DONATIONS:

Let’s turn “I CAN’T” into “I CAN” so that we can cure VCP disease. I can’t walk anymore because of VCP disease, but I can help us find a cure. During the week of June 23rd, I’ve challenged myself to ____________. I do this to raise awareness. I do this to fight VCP disease. I do this in hope of a better future for my family. Donate to my challenge today 2024 I CAN MOVEment (givebutter.com)

I am walking for a cure because my loved one can’t. During the week of June 23rd, I am going to walk a 10K. I’m not doing this alone. Families and friends around the world are joining in. Help my family take steps towards a cure. 2024 I CAN MOVEment (givebutter.com)

I’m part of a movement to Cure VCP Disease. I’ve pledged to raise $1,000 during our virtual move-a-thon. Whatever I raise will be matched, so your donation will be doubled! Will you help? 2024 I CAN MOVEment (givebutter.com)

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OUR 2022-2023 ACCOMPLISHMENTS

2022-2023 Key Programs:

- Continued Year 2 of Natural History Study at Nationwide Children's Hospital
- Presented at ENMC Remote Care and Clinical Trials Workshop – Amsterdam
- Launched the VCP Ambassadors Program - a Patient and Family Advisory Board
- Expanded VCP Research Network to 50 institutions
- Created VCP iPSC cellular models available for drug discovery research projects
- Funded biomarker discovery project with Caltech

2022-2023 Events:

- 2022 Patient & Caregivers Conference – St. Louis, MO
- 2023 VCP Family Connections Conference – Las Vegas, NV
- 2022 and 2023 Annual Celebration and Fundraiser – Atlanta, GA
- Launched Patient and Caregiver Mental Health Webinar Series (6 sessions)
- Facilitated 10 Scientific Focus Group Workshops (reaching over 100 participants)

Cure VCP Disease Publications (co-author and/or sponsored)

- Standard of Care Consortium published in Orphanet Journal of Rare Disease Development of a standard of care for patients with valosin-containing protein associated multisystem proteinopathy - PubMed (nih.gov)
- 2021 VCP Scientific Conference published in Neurobiology of Disease The Cure VCP Scientific Conference 2021: Molecular and clinical insights into neurodegeneration and myopathy linked to multisystem proteinopathy-1 (MSP-1) - PubMed (nih.gov)
- Genetic Review published in Genes Multisystem Proteinopathy Due to VCP Mutations: A Review of Clinical Heterogeneity and Genetic Diagnosis - PubMed (nih.gov)