

**Parent
Project
Muscular
Dystrophy**

PPMD'S 2020 ANNUAL CONFERENCE

– VIRTUAL EDITION

JULY 22 – JULY 25, 2020

#PPMDCONFERENCE



WELCOME TO PPMD'S (VIRTUAL) ANNUAL CONFERENCE

Unprecedented. Uncertain. Trying. Pandemic. Crisis. Social distancing. New normal.

I don't know about you, but these are just a few of the words I hope to never hear again – once we emerge from all of this!

It is an extraordinary time and our always resilient community continues to inspire and energize me. And while we can't connect in person this year, there was no way PPMD could let the summer go without hosting our Annual Conference.

So like everything else these days, we are gathering virtually. From July 22 – 25, we will be offering a packed agenda of many of the sessions you enjoy most at our conference. From clinical trial updates, to the latest advances in Duchenne care, to our work in Washington, D.C., and opportunities to engage with families across the country, this year's Annual Conference will help you catch up on the incredible momentum still happening in our community and reconnect with old friends, while making new ones.

We're also going to have some fun! The PPMD team is organizing a variety of social activities for the whole family so that your virtual conference has a few surprises, and some much needed laughs.

This box that you received is full of goodies from our industry partners who continue to impress us with their commitment to our loved ones with Duchenne. We've also included an overview of the latest PPMD resources so that you can go online and explore some of the invaluable content we provide.

I am heartbroken that we will not be meeting in person this year, but I'm so excited about the interactive, online experience we have put together for you and your family.

As we have said since the beginning of our quarantine back in March – this community, our families, YOU...we're stronger than a virus. We live with Duchenne in our world every day.

Thank you for joining us on this journey. Thank you for joining the fight to end Duchenne!

See you on Zoom!

A handwritten signature in black ink, appearing to be 'Pat Furlong'.

Pat Furlong
PPMD Founding President & CEO

PPMD

RESOURCE GUIDE

Parent JOIN THE FIGHT.
END DUCHENNE.
Project
Muscular
Dystrophy



A Duchenne diagnosis can leave families feeling isolated, overwhelmed, and confused. The most important thing for you to remember is that you are not alone. PPMD is here to connect you to news, resources, advancements in research, and each other.

Now, more than ever, there is reason to hope – hope for therapies, hope for research, hope for care, hope for a cure. We hope that the resources and guidance that we offer here might be helpful for each family member along this journey.

View these resources at
parentprojectmd.org/families



ABOUT DUCHENNE

FOR NEWLY DIAGNOSED

If you are the parent of a very young or newly diagnosed child, please spend time in the Newly Diagnosed section of our site. Let the PPMD family know who you are — we are here for you and want to make sure you have the tools you need to begin this journey. There is a lot of information to absorb and we are here to help you make sense of it. Explore our materials, and when you are ready, do not hesitate to reach out. You are never alone.

parentprojectmd.org/newlydiagnosed

GENETIC TESTING & INFORMATION

Decode Duchenne provides free genetic testing, interpretation, and counseling to people with a suspected or known diagnosis of Duchenne or Becker who are living in the US or Canada. Decode Duchenne also provides free carrier testing to women with a family history of Duchenne or Becker. All testing is performed at our partner laboratory, PerkinElmer Genomics. The program is administered by PPMD's certified genetic counselors, and is presented by Sarepta Therapeutics and supported by PTC Therapeutics.

parentprojectmd.org/decode

ONE ON ONE SUPPORT

NEW in 2020! We are making it easier than ever before to connect with PPMD's genetic counselors regarding your Registry and genetic testing questions. Both genetic counselors managing The Duchenne Registry and Decode Duchenne are board-certified and have extensive experience working with Duchenne and Becker families. Just visit The Duchenne Registry, click on the Calendly link, and select a time slot that is convenient for you — it's that simple!

duchenregistry.org



PPMD COVID-19 INFORMATION CENTER

As the COVID-19 (coronavirus) pandemic continues to evolve and the country slowly begins the process of reopening, PPMD continues to update our COVID-19 Information Center. This resource section was designed to help you and your family navigate this global crisis, including answers to your most pressing questions and fun family activities to help you get through long days (and nights) at home.

parentprojectmd.org/covid19

ASSEMBLING A CARE TEAM

It is extremely important that you work with a comprehensive, multidisciplinary neuromuscular team that has experience and expertise managing all aspects of care for patients and families living with Duchenne. This comprehensive team will allow each specialist to give input into the best and most appropriate care for you and your child.

parentprojectmd.org/careteam

CARE & SUPPORT MATERIALS

At PPMD we strive to equip every family with the most up-to-date care information possible. For this reason, we have dedicated an area of our website to allow for quick access to important resources, including:

- New Diagnosis & Early Care Guide
- Family Care Guide
- Education Matters (now available in 3 volumes specific to age)
- Emergency Care Resources

parentprojectmd.org/supportmaterials

PHYSICAL THERAPY VIDEOS & RESOURCES

PPMD recently unveiled a new series of Physical Therapy Videos and Range of Motion Guide. We all know how critical consistent PT is for people living with Duchenne and this new video series demonstrates the current Physical Therapy Guidelines, PPMD helped develop. Included in the series are recommendations for stretching routines and safe, favorable mobility device positions for both ambulatory and non-ambulatory people living with Duchenne.

parentprojectmd.org/physicaltherapy

CLASSROOM RESOURCES

PPMD wants to make sure that families within our Duchenne community are equipped with the right tools to ensure a successful school year. From IEPs (individualized education programs) to accessibility to what information to provide to whom about your child's medical care, there's a lot to consider and plan. Consider this your Back-To-School Kit, including new editions of Education Matters!

parentprojectmd.org/classroom

COMMUNITY RESOURCE CENTER

The PPMD Community Resource Center is a one-stop online resource for every family living with Duchenne and Becker. Here you can find some great local and national resources, products, and organizations recommended by other Duchenne and Becker families. If you have recommendations of resources to be added, please reach out to us at

resources@parentprojectmd.org.

parentprojectmd.org/resources

INSURANCE ACCESS & COVERAGE RESOURCES

Whether you are seeking coverage for an FDA-approved therapy, need approval from your insurance company for medical devices or equipment, or need assistance with medication and appointment coverage, PPMD has assembled resources to help families and medical providers at each stage of the healthcare access process. PPMD also works directly with organizations that can assist with walking you through the process.

parentprojectmd.org/accessresources

CERTIFIED DUCHENNE CARE CENTERS

PPMD is dedicated to ensuring that all families have access to comprehensive, optimal Duchenne care. For this reason, PPMD started the Certified Duchenne Care Center Program, creating a network of sites capable of providing the highest

level of comprehensive Duchenne care based on published Duchenne CDC care guidelines. Find the site nearest you and learn more about our certification requirements and process.

parentprojectmd.org/carecenters



**29
CENTERS**

across the
United States



**700 CARE
PROVIDERS**

caring for individuals
with Duchenne



**3,300
PATIENTS**

served at
certified centers



**79 CLINICAL
TRIALS**

located at
certified centers



**+1,150 TRIAL
PARTICIPANTS**

currently enrolled or
in active recruitment

END DUCHENNE TOUR

PPMD's End Duchenne Tour focuses on connecting families with leading experts and each other while highlighting the robust work of PPMD and our partners. Tour stops are typically one-day long events and provide updates on the latest clinical trials and early-stage research, care standards, practical resources and opportunities to become involved in PPMD's programs and The Duchenne Registry.

Thanks to the increasing power and reach of PPMD's Connect groups, PPMD expanded the End Duchenne Tour in 2020 to include Connect Group Sessions, which will provide condensed agendas led by Connect Coordinators and allow families to meet and spend time with their Duchenne community.

parentprojectmd.org/tour

PPMD'S CONNECT

No one should be on the Duchenne journey alone, and PPMD has local Connect groups all over the country for this very reason. These regional groups, run by volunteer Duchenne parents and grandparents, serve many functions, but primarily exist to be a source of comfort, support, and information for families in our community. Reach out to your local group and get connected. If a group doesn't exist we can connect you with families in your area. No one needs to go through this experience alone. Finding other families to connect with will help you to know that there is hope and that you have support whenever you need it.

parentprojectmd.org/connect

PPMD'S ADULT ADVISORY COMMITTEE (PAAC)

The PPMD Adult Advisory Committee (PAAC) serves to ensure that the voices of adults living with Duchenne and Becker are reflected in PPMD's legislative, policy, care, and program activities. The 2020 PAAC includes 23 men with Duchenne and Becker and 1 female carrier of Duchenne who serve in a formal advisory capacity. The PAAC has also launched a Facebook group that gives people with Duchenne and Becker (and their loved ones) a safe place to discuss topics that are important to daily life.

parentprojectmd.org/paac



CURRENT RESEARCH



EXPLORE APPROVED & POTENTIAL THERAPIES

Duchenne research continues to progress, with multiple therapies in clinical trial. Stay up-to-date on the latest progress of drug development in Duchenne.

parentprojectmd.org/pipeline



PARTICIPATE IN CLINICAL TRIALS

Learn about actively recruiting clinical trials and studies you or your child may qualify for.

parentprojectmd.org/exploretrials



INVESTING IN INNOVATION

In order to End Duchenne, we must understand Duchenne. PPMD supports numerous scientists and clinicians answering important questions to drive us closer to a cure.

parentprojectmd.org/researchstrategy



JOIN THE FIGHT

JOIN THE DUCHENNE REGISTRY

If you have Duchenne or Becker, care for someone living with Duchenne or Becker, or are a carrier, join The Duchenne Registry to share your data. The Registry recently transitioned to a new and improved smartphone app, so it is easier than ever before to join and update your data. By sharing your data, you become a citizen scientist by advancing research and treatments for Duchenne. Participating in the Registry also helps you learn about and enroll in actively recruiting clinical trials and research studies.

duchenneregistry.org

BECOME AN ADVOCATE

Next year marks the 20th anniversary of the MD-CARE Act which fundamentally changed the Duchenne care and research landscape. Join the fight to end Duchenne by raising your voice in Washington D.C. at PPMD's Advocacy Conference. We also encourage you to sign up to receive Action Alerts, so that you can stay up-to-date with the latest advocacy news, as well as reminders to contact legislators on the most pressing issues throughout the year. We hope you will consider joining us in our efforts to continue the momentum that started two decades ago.

parentprojectmd.org/advocacy



FUNDRAISING EVENTS

We are only as strong as our community and over the past several months your strength has propelled us forward. Help us keep fighting, and together, we will end Duchenne.

RACE TO END DUCHENNE

Join the Race to End Duchenne team by participating in an endurance event and raising much needed funds to support PPMD's mission. Whether you're doing a virtual 5K or training for a major marathon, there are plenty of ways to get involved. Visit our website for a current race calendar or choose your own race and start raising funds and awareness.

racetoendduchenne.org



CREATE YOUR OWN FUNDRAISER TO END DUCHENNE

PPMD's mission is to end Duchenne but we need YOU! Now is the time to set up your personal page, plan a virtual event, or organize a socially distant activity to raise funds to support PPMD. You can do just about anything to raise funds to end Duchenne. And PPMD is here to help you every step of the way.

parentprojectmd.org/diy

COACH TO CURE MD

For over a decade, PPMD and college and high school football teams have partnered to raise money and awareness through Coach To Cure MD. This season may look a little different, however, this tradition continues with multiple ways you and your family can participate on game day — and have a great time doing it. Find out how you can get in the game and join the PPMD team!

coachtocuremd.org



DUCHENNE ACTION MONTH

Mark your calendars for September 2020 when the Duchenne community, once again, celebrates Duchenne Action Month! Each day, PPMD will provide you with a simple, impactful action you and your family can take that will help us in our mission to End Duchenne!

parentprojectmd.org/actionmonth

SHOP TO END DUCHENNE

Raise awareness and look great doing it! Visit PPMD's online store to stock up on the latest merchandise, including shirts, hoodies, backpacks, and running gear. New items added all the time!

parentprojectmd.org/store

THANK YOU TO OUR SPONSORS



Parent Project Muscular Dystrophy

JOIN THE FIGHT.
END DUCHENNE.

Parent Project Muscular Dystrophy fights to end Duchenne for every single family.

ENDDUCHENNE.ORG