Hello 8p Community,

We hope everyone is enjoying the New Year! January was a busy month for our community. The Patient Leadership Board hosted a virtual informational session with Children’s Hospital Colorado, explaining what you can expect from a visit at the 8p Multidisciplinary Clinic. We also released our first quarter Research Update. You can always find recording links below and subscribe to our 8p Youtube Channel.

The Share What Works series is off to a great start. The monthly interactive questions were posted in January, thank you for your participation. Mark your calendars and be sure to register for this month’s interactive session on Saturday, February 26th, at 12:00 pm ET!

Rare Disease Day is Monday, February 28th! Our rare disease ribbon is denim colored. Please wear your denim and perhaps an old Project 8p shirt to show support to our cause!

SAVE THE DATE. With the addition of new Patient Leadership Board members, we are able to host an 8p Family Retreat. We will be meeting August 6th-8th, in Denver, Colorado. Additional details will be released soon.

Below you will find The Narrate Study. This is not an 8p specific study, however as members of the rare community we have been invited to complete this survey. The survey takes approximately 10 minutes. We would appreciate your participation.

The PLB is recruiting a Duplication Representative. As a board we want to represent all 8p diagnoses. Please email Kaiti to learn more about this opportunity.

We look forward to seeing you at the Share What Works session this month!

Together Towards Treatment,

Your PLB
Welcome to new families and big hugs to our community. We are in the midst of implementing our new 5 year strategic plan with some exciting news. Project 8p's 2021 Year End Global Difference Makers Campaign contributed to us raising over $400,000. Donations were doubled and then matched by our family. Moreover, we successfully applied and received several foundation grants and a year 3 grant from the Chan Zuckerberg Initiative of $150,000 to continue our 8p led collaboration for the Commission on Novel Technologies for Neurodevelopmental CNVs. We are committed to financial transparency and you can find our tax filings on our website (*2021 will be added once it is filed).

We sent our Global Difference Makers a video titled "Thank you for giving us a shot" with a story about how our family loves basketball and we hope our 8p heroes can participate in things that they love to do and find meaning. Thank you for giving the 8p heroes a shot to live a meaningful life in good health and to participate in all the things that they love just like you and I.

As each of you continue supporting the Foundation, please know that our goal as an organization is to raise $5 million by 2023 for critical studies which will advance the understanding and treatment of chromosome 8p disorders.

Please celebrate the growing team by reaching out to the PLB, commenting on social media, and saying hello. The Board of Directors and our small team are working hard everyday.

Lots of love,
Bina Shah
Join Us

This is the Share What Works Session you have come to know and love. A chance for us, the 8p experts, to share what really works for our 8p heroes. This quarter’s topic is Education.

Be sure to register.
We will be issuing out 8p swag to one lucky attendee!

Register

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I SUPPORT
RARE DISEASE DAY
28 FEBRUARY 2022
#RAREDISEASEDAY RAREDISEASEDAY.ORG

Rare Disease Day
8p's rare disease ribbon is denim colored. Please wear your denim and perhaps an old Project 8p shirt to show support to our cause!

If you use social media to spread awareness be sure to tag us and use the hashtags:

#RareDiseaseDay  #project8p  #8pdisorders  #8pheroes

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The Narrate Study seeks to survey patients and families experiencing rare diseases to identify potential commonalities among the needs faced by heterogeneous communities. The survey takes approximately 10 minutes to complete.

Please be sure to mark Chromosome 8p Disorder on the survey.

*This is not an 8p specific study, however as members of the rare community we have been invited to complete this survey.
Free Introduction to Gene Therapy Webinar

The American Society of Gene + Cell Therapy and The National Organization for Rare Disorders are offering a free virtual education session on gene therapy.

See the agenda and learn more at the link below.

*Project 8p is not hosting this event.*
First Quarter Research Update
The Quarter 1 update is an introduction to this series. You can expect more content from the quarter 2 update in April. As always, we value your feedback and are happy to answer additional questions. Please feel free to email us at the link below.

Feedback/Questions

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**Informational Session with Children’s Hospital Colorado**

Questions

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*We Want to Hear from YOU*
Do you have an idea that could help the 8p community?
No idea is too big or small, please email us at the link below.

Volunteers Needed

Join parents like you as a warrior for the cause.
Fill out the form below!

*|NPO_NAME|
*|NPO_ADDRESS|

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