



spectrum

PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME



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P R E S I D E N T ' S M E S S A G E

IT IS HARD TO BELIEVE THAT WE ARE QUICKLY APPROACHING THE HOLIDAY SEASON AND THE CONCLUSION OF 2019. IT SEEMS LIKE EVERY YEAR GOES BY FASTER THAN THE PREVIOUS YEAR. 2019 HAS BEEN A BUSY YEAR OF TRANSITION WITHIN PRISMS.

PRISMS hired its second Executive Director, Casey Gorman, in July. The Board of Directors is excited to have Casey on the team! Casey has hit the ground running and we look forward to the contributions she will make to PRISMS and the SMS community in the future.

This fall, PRISMS, along with the SMSRF, hosted a successful Research Symposium in Houston. This event allows all those researching different aspects of SMS to get together and communicate outcomes and foster collaboration for future research initiatives. Plans are already underway for the next Research Symposium in 2021!

PRISMS completed its first ever educational webinars this year. Board member

Allison Stephanouk and the other volunteer members of the Education committee have pulled together great content for each of these webinar sessions. These public webinars are a first for PRISMS, but something that the community indicated was needed. Check out the summary of our webinars in this issue of the Spectrum and look for even more in the future.

2020 will be another important year for PRISMS and the SMS community, culminating with the Conference in Dallas in July 2020. The Conference remains the most important program our organization offers to the greater SMS community. The impact of this program is not only vitally important for families, but also for researchers, teachers, doctors and caregivers. We believe this will be our largest Conference yet and we hope you are planning to join us!

In this season of Thanksgiving, there are many items to reflect upon and

be thankful. As an SMS parent I am thankful for this organization and the vision of its founders. We all have "our story" of when the diagnosis of SMS was received and how important PRISMS was to help with the understanding of SMS. I am thankful for all those who donate their time and money to increase awareness for SMS. Webinars, Conferences, Symposiums, the patient registry....all of this cannot happen without the necessary financial support. Most importantly I am thankful for all of the families, volunteers and staff that make PRISMS what it is today and I look forward to the positive impact that PRISMS will continue to provide in the future.

Wishing you and yours the best this Holiday season!

Thank you,
Brandon Daniel
President





The ED Corner

By Casey Gorman, Executive Director

It has been a whirlwind three months with PRISMS so far! I feel incredibly grateful to be working with an organization that is part of such a dedicated and wonderful community. Thank you so much to the PRISMS family I have met so far. I have learned a lot about Smith Magenis Syndrome in these first three months and I look forward to learning even more as I get to know all of you.

We are nearing the end of 2019, which means that it is time to reflect on what we have accomplished this past year and think about what we hope to do next year. The hallmark event of the year for me is the 10th Research Symposium, which we hosted in partnership with the Smith Magenis Syndrome Research Foundation. This event brought our organizations together to help highlight the best and brightest researchers working to better the future of Smith-Magenis Syndrome. We saw the most attendees and abstract submissions ever in the history of the event, and we are hopeful that research into SMS will continue to grow. We also held a very successful meeting with our PAB, where we laid out

plans to continue expanding our Patient Registry and SMS Clinics. I look forward to being able to share much more good news with you from the research world in 2020!

PRISMS launched two new programs this year – the Webinars and the Clinic Travel Fund. Both programs are designed to help connect our families with resources that they otherwise might not have access to, since SMS professionals are still few and far between. The Clinic Travel Fund provides up to \$300 per family to help offset the cost of travel to one of our SMS clinics. The Webinars are quarterly web conferences where professionals present and answer questions on various topics. Read our feature on page six to hear all about this year's webinars!

2020 is an exciting year, as PRISMS prepares to host its next International Conference in Dallas, Texas (July 30th -August 1st). Save the date! I can't wait to see you all there.

STORIES FROM THE RESEARCH SYMPOSIUM

The 2019 symposium was the largest gathering of SMS researchers to date and we were pleased to see that the interest in studying SMS is expanding and making inroads in new research disciplines. We welcomed almost sixty attendees to the symposium and a total of nineteen abstracts were presented (fifteen talks and four posters).

All of the abstracts from our Symposium are available to review on the PRISMS website. We are incredibly encouraged by the astounding participation and interest from the research community in this year's symposium, and hope to continue to encourage new researchers to get involved in SMS research through our Symposium and other research efforts.

This year, PRISMS funded travel for three early career researchers to attend the Research Symposium. Read on to see what they had to say about this year's event!

FRANCIS JAMES GORDOVEZ

Thank you very much PRISMS and SMSRF for the invitation and the support to attend the 10th SMS Research

Symposium. I met experts devoted to studying SMS and exchanged ideas with other scientists coming from different disciplines. I was also able to share my findings regarding my research on cellular models for SMS. More importantly, I was able to learn more about people living with SMS and the experience of their caregivers. Now, long hours in the laboratory are certainly more worthwhile knowing that in my own little way, I may be able to contribute to the growing knowledge which will someday improve the lives of people living with SMS. May you continue enabling a collaborative research environment. I look forward to joining you again at future conferences!



Francis James Gordovez, MD, Pre-Doctoral IRTA Fellow, National Institute of Mental Health, National Institutes of Health

PRISMS and SMSRF co-hosted this research symposium.

GEORGIA AGAR

Attending the 10th SMS Research Symposium hosted by PRISMS and the SMSRF was a brilliant experience for me as an early career researcher. Myself and my colleague are based in the UK and were pleased to be able to meet so many researchers from the International SMS community, as well as parents and stakeholders with a shared interest.

The initial welcome event was an excellent opportunity to meet like-minded researchers and discuss ideas in a relaxed setting. I also really benefited from the opportunity to share the findings from my PhD research –investigating the longitudinal sleep profile in children with SMS – in a welcoming environment. The questions and comments from researchers and professionals across disciplines were invaluable and have helped

me to develop my ideas for my thesis further.

Additionally, the open discussion session amongst attendees was very useful, and the conversation around methods and approaches to assessing sleep in individuals with SMS will inform my future research proposals.

I am very grateful for the opportunity to present, and to PRISMS for the bursary. Thanks again for a wonderful time at the conference!



Georgia Agar, MSci, Doctoral Researcher, Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham



Osman in discussion with Maggie Miller and Ann Smith



OSMAN UMJARI

Attending the PRISMS Research Symposium in Houston was an incredible experience. Ever since my son, Malik, was diagnosed with SMS five years ago, I have wanted to participate in research on Smith-Magenis syndrome. Having just completed my doctorate, the research symposium was the perfect opportunity to learn about the latest SMS research, network with researchers, and forge relationships that I hope will lead to promising collaborations in the near future. With my expertise in psychology and statistics, I hope to conduct research on numerous topics, including sleep, parenting practices, behavior, executive function, and educational environments and outcomes.

As a parent of a child with SMS, attending the symposium gave me hope for the future of my child and SMS children everywhere. As all SMS families struggle to cope with the challenges of the syndrome, seeing some of the brightest minds in the fields of genetics, psychology, and biology put their efforts towards alleviating the symptoms of SMS and discover long term

solutions that may restore functionality of compromised neurobiological systems gives me so much optimism that our children will thrive in ways we never imagined. I am incredibly grateful to PRISMS for supporting me to attend and benefit from the research symposium.

Osman Umajri,
Researcher and SMS parent



SMS Research Foundation and PRISMS



Symposium attendees (above) and a presentation on new studies of SMS.

Spreading the Word— PRISMS Webinars

By Allison Stephanouk

PPRISMS' newest committee, the Education Committee, launched PRISMS Webinar Series this year. As an extension of PRISMS biennial conferences, this program was designed to bring educational information and resources about Smith-Magenis Syndrome to the community at large in a more dynamic way and promote engagement between families and professionals. Committee members include Allison Stephanouk (Chair), Maggie Miller, Sylvia Farber and Amy Pereira.

Since the start of the program in June 2019, three webinars have been successfully broadcast. Webinars are moderated by Allison Stephanouk. Allison is a PRISMS board member, the Regional Representative for the state of Georgia, and mom to Natalie, who is nine years old with SMS.

PRISMS' first webinar was exclusively for PRISMS Regional Representatives and was broadcast on June 12th. Presenters included Percy Huston, the founder and coordinator of PRISMS's Regional Representative Program, as well as board members Denien Rasmussen, Diane Erth, and Tina McGrevy. Some of the topics covered in this webinar were regional representative responsibilities, tips for hosting fundraisers and meetups, and resources for regional representative to share.


The second webinar on June 22nd, was the Patient Registry Webinar. Theresa Wilson MS, RD, PRISMS Research Coordinator, presented information on what the SMS

Patient Registry is, how the information provided is used, and how families can enroll using the new electronic consent form.

On August 6th, PRISMS' third webinar, Understanding the Genetics of Smith-Magenis Syndrome, was presented. Rachel Franciskovich, MS, CGC, PRISMS Genetic Counselor, was the speaker for this webinar. She began with a basic lesson on genetics and shared specifics on the genetics behind SMS.

PRISMS' next webinar, The History of Smith-Magenis Syndrome featuring Ann Smith, was unfortunately postponed due to illness. A new date for this webinar will be released shortly. Ann will discuss the history of Smith-Magenis Syndrome and the importance of what we have learned through research. Ann is a founding member of PRISMS and chaired the Professional Advisory Board (PAB) until 2011. She now serves as PAB

Emeritus Chair, and has dedicated over 3 decades of her professional career to the study of SMS, the syndrome she co-discovered in the early 1980's.

Plans for upcoming webinar topics include sleep, education, medication, new research, and many more. A listing of upcoming webinars as well as recordings of all past webinars can be found on prisms.org under the education tab. In the future, PRISMS webinars will also be available on PRISMS YouTube channel. Be sure to subscribe to PRISMS, Inc. on YouTube (<https://www.youtube.com/channel/UC2Bk1GSVTyAIG9nZXiCloOw>) 



A YEAR IN REVIEW— COMMUNITY HIGHLIGHTS

The PRISMS community has been hard at work and having fun throughout 2019! Take a look back at some of our community events this year.

Organize your own event and want to be featured next year? Make sure to let us know about your event! Reach out to info@prisms.org. We would love to help make your meet-up or fundraiser a success.

ABC FUNDRAISER

This past May, Denien Rasmussen, Kyle Rohde, and Aileen Rohde hosted their 3rd annual ABC Fundraiser at the iPic Theatre in South Barrington, IL. The event featured many raffle items, a silent auction and a 50/50 raffle. Over 50 people attended, including 9 SMS families, and they raised over \$9,000 for PRISMS.

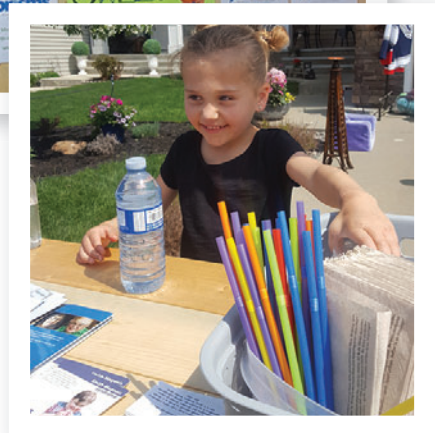
Per Denien, “We had a great turn out and everyone had a great time. Some new SMS families were in attendance and it was the first time they met anyone besides their child with SMS. This support for each other is key in our community.” Thank you to the Rohdes and Rasmussens for everything that you do!



LEMONADE STAND

On May 25th, Ryan and Nikolas Michaud hosted a lemonade stand in Edmonton, Alberta, Canada to bring awareness to Smith-Magenis Syndrome and raise money for PRISMS. They did this in support of their sister Jillian Michaud. They raised over \$400 Canadian (approximately \$315 USD). Thank you so much, Ryan and Nikolas!

(Continued)



A YEAR IN REVIEW—COMMUNITY HIGHLIGHTS

LEGOLAND

Sixteen families from five southeastern states met this past August at Legoland Discovery Center in Atlanta. For some families, this was their first time meeting another SMS family! Thank you to Allison Stephanouk and Lesslie Carnahan for organizing and Dr. Mark Lawrence and Ginny Lawrence for volunteering at the event. We appreciate all of the families who attended and helped make the Legoland SMS meet-up a huge success!



MISSION BAY MEET-UP

Our Southern California families get together twice a year to raise money, to connect with other families and celebrate the victories of everyday life with hugs and community. Thank you to Diane Erth for organizing and all of the families who attend!



HOUSTON PICNIC

The 16th annual Houston SMS picnic was held at Bear Creek Park in Houston on Sat. Nov. 9th. They had 49 attendees (12 who have SMS--ages 18 months up to 33 years). Special thanks to Keith and Karen Miller who brought the yummy burgers and dogs (and especially Keith for his hard work--we really appreciated your grilling skills). Thank you for everything you brought, but most importantly for being there in fellowship with all of the families.

A big thank you to the Baylor College of Genetics medical students (under the leadership of Dr. Lorraine Potocki) for watching all of the children on the evening of Friday, November 8th so the group could enjoy an evening of fellowship.



UCSD MEET-UP

Dr. Gail Reiner worked with the UCSD developmental pediatrics team on November 8th to educate rising physicians about Smith-Magenis Syndrome. Attendees included UCSD pediatric residents, developmental pediatrics fellows and senior physicians for developmental pediatrics (Dr. Marty Stein and Dr. Teddy Nelson). Also helping at the event were Ms. Kasey deMaude, her son Boston Gritman, and Dr. David Reiner. Thank you to all for spreading knowledge about SMS! 🌊

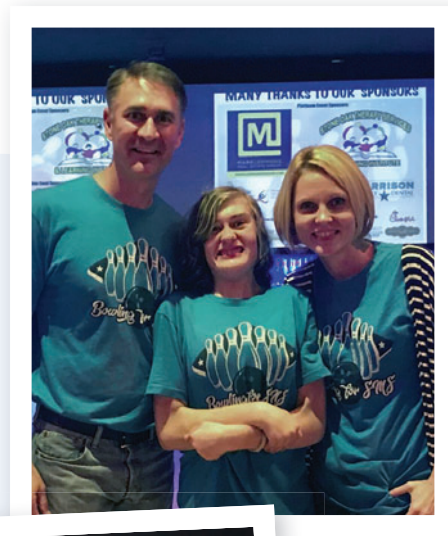




SMS AWARENESS
FUNDRAISER

The original Bowling for SMS event is in its 10th year and grows each year! This year the event had over 300 in attendance and raised over \$27,500 to further PRISMS' goals of raising awareness, increasing education, and supporting research. Sylvia and Jeremy Farber organize this event each year in San Antonio, Texas. They are the parents to Austin, 16, with SMS. Also in attendance each year are 3-4 other SMS families from San Antonio.

In an effort to extend the reach of this family friendly fundraiser, Bowling for SMS expanded to include PRISMS members from across the country to fundraise during the month of November. Everyone who signed up promised to bowl sometime between November 17th and November 30th. We had 9 domestic and 1 international participants, raising over \$10,000! This was our first year promoting a peer-to-peer fundraiser of this nature, and it was a great success! We can't wait for next year! Thank you to everyone who signed up and everyone who supported a bowler! Special thanks to Sylvia Farber, who inspired the effort with her successful annual bowling fundraiser and helped spearhead the event.

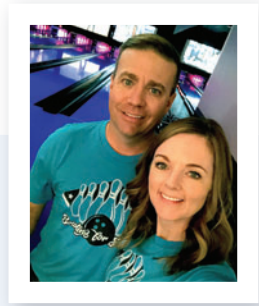


Take a look at some of our bowlers in action!

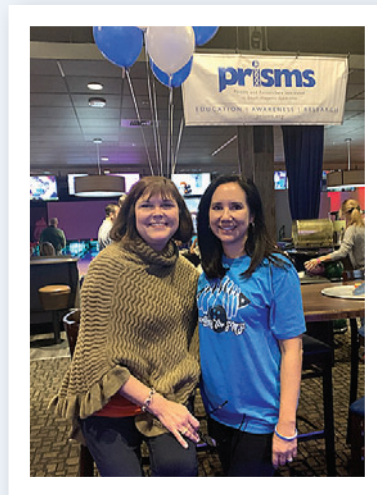
Bowling for SMS Columbus, GA was held at Stars and Strikes on November 17th. Over 100 guests attended this first annual event. Bowlers competed for prizes for the top 1st, 2nd, and 3rd place highest bowling score. Guests also tried their luck at the 50/50 raffle, with one happy winner walking away with the cash prize. Over \$6000 was raised at the event!

Special thank you to the event chairs, Lesslie Carnahan and Allison Stephanouk, and the event sponsors: Columbus Speech and Hearing, Rivertown Pediatrics, Exceptional Advocacy Services, Mark Lawrence Pediatric Dentistry, and Stars and Strikes.

See you at the bowling alley next year! 🎳



PRISMS Board members Brandon Daniel (left) and Denien Rasmussen (right) went and bowled with friends and family for SMS Awareness Day.



THE PRISMS CONFERENCE PREVIEW



Envisioning the Possibilities

11TH INTERNATIONAL CONFERENCE | DALLAS, TX

When: Thursday, July 30, 2020 – Saturday, August 1, 2020

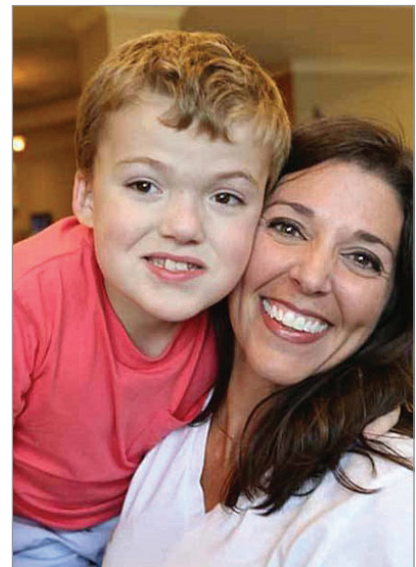
**Where: Hyatt Regency Dallas
Dallas, TX**

Start making your plans to attend the PRISMS conference! We welcome families and researchers from around the globe to spend a few days together learning about new research and interventions regarding Smith-Magenis Syndrome in a caring and supportive environment. The city of Dallas provides a wonderful backdrop for our event, with many local attractions and sites to include in your stay while at the conference.

The International Conference is PRISMS' foremost program, encapsulating its mission of Education, Awareness and Research within the framework of the

event. The biannual PRISMS conferences are the largest event dedicated to SMS and provide outreach to our community across the world!

Many volunteer hours are dedicated to the planning and execution of the conference, and PRISMS subsidizes almost 70% of the conference costs. This combination of generous volunteerism and fundraising translates to much lower conference fees for attendees. Scholarships will be available to help families attend the conference as well as grants for professionals to attend the Teacher & Staff Training Workshop and conference.



CONFERENCE DETAILS

Sessions begin Thursday, July 30, 2020*

Childcare & the PRISMS Den open.....	1:00pm
First Steps session begins.....	1:15pm – 2:45pm
Workshops begin.....	1:30pm – 4:30pm
Reception	5:00pm – 7:00pm

We will offer several workshops on Thursday. These include:

- Adult Living Workshop: including living options, vocational training, and medical concerns (open to all)
- Teacher & Support Staff Training Workshop: (open to all)
- The First Steps Session: (for first or second-time attendees only)
- Full day sessions will be held on Friday and Saturday, July 31- August 1, 2020.
- Sessions end on Saturday, August 1, 2020 at 6:15pm.

* Please note times may vary slightly.

Hotel room reservations will open in January 2020.

Hotel guest room rate: \$149/night.

Conference Registration will open in Spring 2020.

Conference registration costs:

Adult	\$260.00
Child	\$100.00
Individual with SMS	\$75.00
Professional	\$315.00

Please look for our conference campaign to begin next year:
#EnvisioningMyPossibilities!

Watch for more details to follow in the months ahead through the PRISMS website, emails, Facebook and Twitter. We hope to see you there!

For questions: conference2020@prisms.org



The PRISMS community (above) enjoying the 2018 conference with learning, fun, family, and mutual support.

Join the SMS Patient Registry

Have you signed up to participate in the Smith-Magenis Syndrome Patient Registry?

The Smith-Magenis Syndrome Patient Registry is an online tool used to collect, organize, and store detailed information about Smith-Magenis Syndrome (SMS). This information will be used to help improve the clinical management and quality of life of all individuals with SMS.

Why do we need a registry? A patient registry will allow researchers to more accurately determine the natural history of Smith-Magenis syndrome by collecting information and making the data available to researchers across the globe. The aim of this registry is to collect as much information as possible from patients and families affected by SMS to accelerate research, which may lead to treatment trials and improved therapeutic options.

Who is eligible to participate? All individuals with a confirmed diagnosis of Smith-Magenis Syndrome are eligible to participate!

All surveys and questionnaires in the registry can be completed electronically—no travel is needed to participate.

How do I enroll? If you are interested in enrolling or have questions about this study, please contact Theresa Wilson or Dr. Sarah Elsea via email at PRISMS.Registry@bcm.edu or by phone at 713-798-5689.





Parents and Researchers Interested
in Smith-Magenis Syndrome

EDUCATION | AWARENESS | RESEARCH

prisms.org

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CONNECT WITH PRISMS

Host a fundraiser or awareness event in your area

Check out our fundraising ideas at:

<https://www.prisms.org/who-we-are/get-involved/fundraising/>

Contact info@prisms.org for support and ideas to make your event a success.

Make a donation

Support PRISMS' mission to increase awareness, education, and research for the SMS community by visiting our website and making a donation today at

<https://www.prisms.org/donate/>

Share your story with us

We want to hear from you. Reach out to us at

info@prisms.org

VOLUNTEER OPPORTUNITIES

PRISMS is always looking for helping hands from the community to serve as members of one of our various committees, assist in a program, or coordinate an event. Interested in sharing your time and talents with the SMS community? Contact us at info@prisms.org for more info about our current openings or other volunteer opportunities.

Current Openings

Awareness Committee: PRISMS is seeking active volunteers to help gather and write up stories from the community for the Spectrum Newsletter and/or social media. Solid writing skills and familiarity with PRISMS current social media a plus.

Conference Committee – Exhibitors and Sponsor:

The Conference Committee is seeking a volunteer to coordinate exhibitors and sponsors for the upcoming 2020 International Conference. This would include identifying exhibitors, vendors, and sponsors, coordinating contact, and ensuring proper appreciation/signage at the conference. 🌐



Follow us on Social Media

Facebook: <https://www.facebook.com/SmithMagenisSyndromePrisms>

Instagram: <https://www.instagram.com/smsprisms/?hl=en>

Twitter: https://twitter.com/prisms_sms

YouTube: <https://www.youtube.com/channel/UC2Bk1GSVTyAIG9nZXiCloOw>

EASY SUPPORT FOR PRISMS

Support PRISMS while you shop. Amazon will donate 0.5% of the price of eligible AmazonSmile purchases to PRISMS.

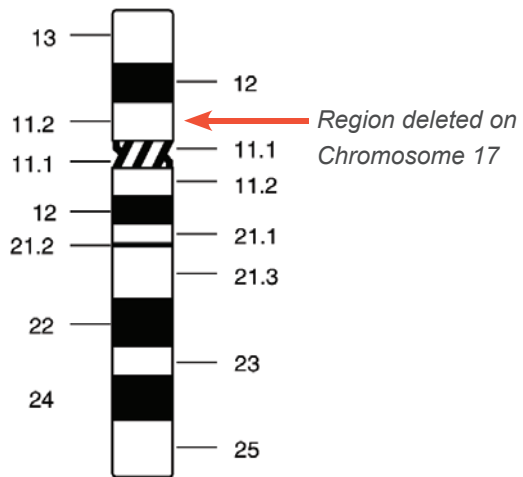
AmazonSmile is the same Amazon you know—same products, same prices, same service. Follow these simple steps to support PRISMS while you shop!

1. Go to <http://smile.amazon.com>
2. Type “PRISMS, Inc.” in the pick your charitable organization text box. Click Search. (Note: type PRISMS in capital letters.)
3. Select “Prisms, Inc.” There are a few organizations with the same name. Choose the PRISMS in Sterling, VA founded in 1993. Click “about” if you want to confirm you have chosen the correct PRISMS.
4. Save <https://smile.amazon.com> to your bookmarks or favorites bar to make it easy to return to AmazonSmile. In order for PRISMS to receive a percentage, you must shop through <https://smile.amazon.com>.
5. Share with friends and family.
6. Enjoy shopping knowing you are supporting PRISMS!



What is Smith-Magenis Syndrome?

Smith-Magenis Syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2.



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