



PRISMS Clinic
and Research
Consortium

Smith-Magenis Syndrome Consortium Clinics



prisms

PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

What You Should Know

Smith-Magenis Syndrome Consortium Clinics

What is the PRISMS Clinic and Research Consortium (PCRC)?

Clinics within the PCRC provide multi-specialty, comprehensive and compassionate care for patients with SMS. The clinics provide



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families an opportunity to receive medical and clinical care and/or treatment recommendations that they can carry home to their local providers of care and that address the challenges and health concerns associated with Smith-Magenis Syndrome. The clinics' approach to care includes consultation with other treat-

ment specialists as needed while developing a plan of care for each patient that strives for health and well-being.

How many clinics are there?

There are currently nine clinic locations within the consortium.

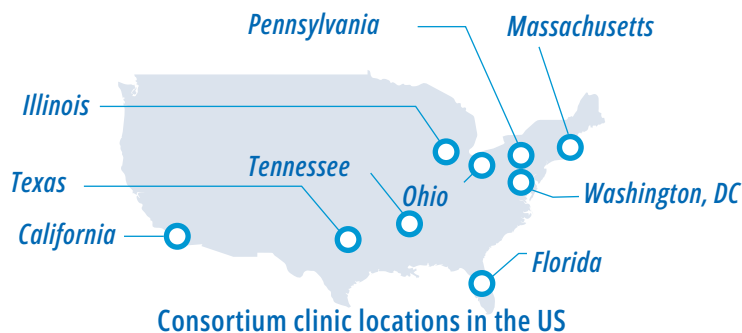
They are located in California, Florida, Illinois, Massachusetts, Ohio, Pennsylvania, Tennessee, Texas, and Washington DC.

I don't see a clinic near me, will there be more clinics?

PRISMS is working to establish additional clinics throughout the U.S. Families can assist with this effort by informing PRISMS of any doctor, especially those affiliated with a hospital, who has demonstrated a consistent interest in SMS. PRISMS staff and advisors will then follow-up with the doctor to determine if they might be a good applicant to the PCRC.

How do I know which clinic I should go to?

Families should be aware that each clinic is unique and do not necessarily offer identical services. In most instances, families should plan to visit the nearest clinic. However, if you have questions about whether the clinic will be able to address your child's specific needs, we encourage you to reach out to the clinic using the contact information on the PRISMS website. Note that each clinic's medical and/or clinic director has a different background and, in most cases, you will find details about their training, experience and specialization on the hospital's website.



Some clinics may provide telehealth visits, but specific rules and insurance restrictions may apply.

What does an SMS clinic visit include?

Each clinic will be different in how they structure a patient visit. All patients will be seen by a medical professional. Some clinics will arrange for any other needed specialists to be available on the day of the visit. Other clinics will provide a referral, or referrals, to other specialists and families will need to schedule follow-up appointments. Questions about what to expect during a clinic visit are best directed to the clinic coordinator in advance of the appointment.

Is there funding available for a clinic visit?

The PRISMS SMS Clinic Travel Fund Reimbursement Program supports families who need to travel to one of the clinics within the PCRC. This fund will help defray costs for travel, (airline or mileage support), lodging costs of other miscellaneous costs attributed to traveling to a clinic. This reimbursement is available to a family only one time. If you are planning a clinic visit and need financial assistance, please email info@prims.org for an application.

How much support does the reimbursement provide?

PRISMS will offer travel reimbursement up to \$300 if an application is approved. Approved funding will require receipts to be submitted and an expense form to be completed. A Proof of Clinic Attendance form must be signed by a clinic staff member and turned in with receipts to PRISMS. Please note that this funding does NOT cover the cost of the visit itself.

How do I make an appointment?

To make an appointment, simply call or email the clinic you wish to attend. All SMS clinic contact information is listed in this brochure and on our website. We encourage parents and other caretakers to clearly communicate their needs and expectations to clinic staff in advance of their initial appointment. You should be aware that some, if not all, clinics may offer a telemedicine option in lieu of in-person clinic visits. You may need to complete intake form, provide genetic testing and have access to prior medical records, labs and developmental testing, if available.

How long does it take to get an appointment with an SMS clinic?

Wait times vary from clinic to clinic, but, in some instances, families should be prepared to wait up to 6 months for a non-crisis appointment.

Clinic Contact Information

You can find an up-to-date listing of all of the consortium clinics and their contact information on our website at: <https://www.prisms.org/about-sms/living-with-sms/sms-clinics/>

SAN DIEGO, CA
**San Diego Pediatric Neurology/
Smith-Magenis Clinic
Rady Children's Hospital**

Address:

3030 Children's Way
San Diego, CA 92123

Ages seen: All

Clinic Director: Dr. Gail Reiner, DNP, FNP-C

Physician Consultant: Kristen Wigby, MD

Clinic Coordinator: Janice Balagtas

Email: gereiner@health.ucsd.edu

Phone: 858-966-5819

Web: <https://www.rchsd.org/>

LEWISBURG, PA
**Geisinger SMS Clinic
Geisinger Department of
Developmental Medicine**

Address:

120 Hamm Drive
Lewisburg, PA 17837

Ages seen: Children and Adults

Clinic Director: Barbara Haas-Givler, MEd, BCBA

Medical Director: Thomas Challman, MD

Clinic Coordinator: Megan Zieber, MS, MPH, LGC

Email: mzieber@geisinger.edu

Phone: 570-551-6968

Web: <https://www.geisingeradmi.org/>

CHICAGO, IL
**Smith-Magenis Clinic
Rush University Medical Center**

Address:

1725 W. Harrison Street, Suite 718
Chicago, IL 60612

Ages seen: Children and Adults

Medical Director: Elizabeth Berry-Kravis, MD, PhD

Clinic Coordinator: Angel Wang

Email: angel_wang@rush.edu

Phone: 312-942-4036

Web: <https://www.rush.edu/>

MEMPHIS, TN
**St Jude/LeBonheur SMS clinic
St Jude Children's Research Hospital**

Address:

262 Danny Thomas Place, Mailstop 760, Memphis, TN
38105

Ages seen: 0-30 in person, older patient by telemedicine

Clinic Director: Andrea Gropman, M.D.

Medical Director: Andrea Gropman, M.D.

Clinic Coordinator: Jean Laboe, MSN, RN

Email (for appointments):

jean.laboe@stjude.org

Phone: 901-595-1211

Web (clinic or general institution):

<https://www.stjude.org>

LEXINGTON, MA (Greater Boston)
**Lurie Center for Autism Massachusetts
General Hospital
MassGeneral Hospital for Children**

Address:

1 Maguire Road
Lexington, MA 02421

Ages seen: All

Medical Director: Ann Neumeyer, MD

Email: LurieCenter@partners.org

Phone: 781-860-1730

Web: www.luriecenter.org



PRISMS, Inc. | 205 Van Buren Street Suite 120 #1027 | Herndon, VA 20170
Email: info@prisms.org | Phone: 972-231-0035 | www.prisms.org

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HOUSTON, TX **Smith-Magenis Syndrome Clinic** **Texas Children's Hospital**

Address:

6701 Fannin Street, 16th Floor
Houston, TX 77030

Ages seen: All

Clinic Director: Rachel Franciskovich, MS, CGC

Medical Director: Lorraine Potocki, MD, FACMG

Clinic Coordinator: Rachel Franciskovich, MS, CGC

Email: smsclinic@texaschildrens.org

Phone: 832-822-2100

Web: <https://www.texaschildrens.org/>

WASHINGTON, DC **Smith-Magenis Syndrome** **Multidisciplinary Clinic** **Children's National Hospital**

Address:

Takoma Theater
6833 4th Street NW
Washington, DC 20012

Ages seen: 6 mos. to 65 yrs.

Medical Director (acting):

Sinan Omer Turnacioglu, MD

Temporary Clinic Coordinator:

Sinan Omer Turnacioglu, MD

Email: Sturnaci@childrensnational.org

Phone: 202-476-6249

Web: <https://childrensnational.org/departments/center-for-neuroscience-and-behavioral-medicine/programs-and-services/neurogenetics-program>

GAINSVILLE, FL **UF Center for Autism and Neurodevelopment** **Smith-Magenis Syndrome Clinic**

Address:

4197 NW 86th Terrace, 3rd Floor
Gainesville, FL 32606

Ages seen: Lifespan

Clinical Director: Kerri Peters, PhD, BCBA-D &

Timothy Vollmer, PhD, BCBA-D

Medical Director: Takahiro Soda, MD, PhD, FAPA

Clinic Coordinator: Mary Kleckner, MSW

Email: UFcan-referrals@shands.ufl.edu

Phone: 352-265-9177

Web: <https://ufhealth.org/locations/uf-health-center-for-autism-and-neurodevelopment#>

CINCINNATI, OH **Cincinnati's Children's Hospital** **Neurobehavioral Psychiatry Clinic SMS**

Address:

5642 Hamilton Avenue
Cincinnati, OH 45224

Ages seen: Children (0-17.5 years old)

Medical Director: Katie Harris, MD

Email: neurobehavioral.clinic@cchmc.org

Phone: 513-636-6553

Web: [Cincinnati Children's Hospital Medical Center](http://www.cincinnatichildrens.org)
www.cincinnatichildrens.org



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