



National Organization of
Vascular Anomalies

The Faces of PHACES Campaign

Thank you for your interest in sponsoring an event for the FACES of PACES Campaign of NOVA. NOVA is a non-profit organization that provides information and assistance to individuals affected by vascular anomalies.

PHACES is an acronym used to describe an association of symptoms with hemangioma.

- P- posterior fossa malformations of the brain
- H- hemangioma
- A- arterial anomalies,
- C- co-arcuation & cardiac defects
- E- eye abnormalities
- S- sternal cleft defects.

The symptoms and severity of PHACES varies from patient to patient.

NOVA launches this campaign to raise awareness and support for PHACES as a growing number of children are diagnosed with this disorder. For more information on NOVA and PHACES visit our web sites at www.novanews.org and www.phaces.org.

The money raised in the Faces of PHACES campaign has been restricted to use in the following ways.

1. The first \$10,000.00 will be set aside for a PHACES Conference to be hosted at Texas Children's Hospital November 2009.
2. The next \$5,000.00 will also be used for Conference related expenses but is not restricted to the Texas Children's Hospital event.
3. After achieving our first \$15,000.00 goal all money will be used for research and education of PHACES.

National Organization of Vascular Anomalies

1. Getting Started: There are two ways you can help.

- **Direct Donations to NOVA-Faces of PHACES:** Direct Donations can be mailed to: NOVA-Faces of PHACES c/o Karla Hall PO Box 0358 Findlay, OH 45840
- **Host a Faces of PHACES campaign event.**

2. Create an Event: there is no limit to the ideas that can be turned into successful fundraising campaigns. A few ideas are listed below.

Ask for Donations to attend:

- **Host a Sunday Brunch**
- **Create a wine tasting and cheese evening**
- **Have an old fashioned BBQ for family and friends**
- **Host Movie Night, NFL kick off party or Super Bowl Party**
- **Host a Family Game night**
- **Host a Harvest or Halloween party for neighborhood kids**
- **Have a swimming pool- have a pool party**

- **Host a Birthday Party- in Lieu of gifts ask for cash donations to NOVA**
- **Do the same for any holiday party.**
- **Sponsor a 5K race**
- **Sponsor a raffle**
- **Sponsor a silent auction**
- **Getting Married? Replace table gifts with place card stating you have made a donation to NOVA**
- **Own a business or have friends that do- ask if you can place a donation jar on the counter.**
- **Send out a personal plea letter to your family holiday card list, ask for donations to NOVA, provide information on NOVA and your own personal story.**

3. Send Event Idea and Proposal to NOVA along with a standard fundraising agreement. Once you have decided on the type of event you want to host you will need to notify NOVA or the Faces of PHACES organizers. If this is a new event you will need to complete a Third Party Fundraising agreement outlining the event. If this is part of a larger campaign you will just need to agree to the fundraising terms listed on the last page of the Third Party Agreement. **(See Attachment A)**

4. Invite friends and family to attend your event: Send out a invite like the one below. NOVA has .pdf files which can be downloaded and printed to provide information on the organization. **(see Attachment B)**

- Explain how the admission to the event is a donation.
- Involve your family: try to coordinate events with family members in other cities- make it a competition of who can raise the most money.

National Organization of Vascular Anomalies

Sample Invite:

**You Are Invited
To attend a Brunch to Benefit
The National Organization of Vascular Anomalies & Faces of PHACES campaign
Given by Janet and Andrew
1234 Main Street, Anywhere USA, 12345
Monday October 1, 2007
RSVP 123-456-7890**

Dear Friends,

As many of you know, December 23, 2005 was a day that drastically impacted the rest of our life. That day, when Rachel was not even 3 months old, the doctors at Children's Hospital told us that Rachel has multiple hemangiomas on her brain and "IT DOES NOT LOOK GOOD." Those words will be hard to forget. We were told that Rachel has a very uncommon medical condition called PHACES. After a few more doctors reviewed Rachel's MRI the next day, we were told there are no hemangiomas on her brain, but many in other places in her skull and little body.

We have been so fortunate that her treatment is now in maintenance mode although we still go for regular visits to a team of doctors including a hematologist, ENT, ophthalmologist, neurologist, pediatrician, plastic surgeon, and neurosurgeon.

Worldwide less than 500 people have been diagnosed though we suspect the numbers are higher. From the beginning of this journey we have been huge advocates of sharing all we can so that the medical community can figure out what causes this association of physiological abnormalities. We have enrolled Rachel in medical research efforts to help them find some answers. Much research is being conducted about PHACES but nothing is definitively known and researchers and doctors continue to use what limited resources they have to understand why PHACES occurs.

NOVA is one of very few organizations that is working to learn more about PHACES and help families who have children who are being diagnosed with this. For more information, check out the website link below and click on "Resources".

We are committed, along with several other families throughout the US and Canada, to raise \$15,000 to help develop the first ever PHACES conference at Texas Children's Hospital in November 2008 for families and medical professionals. Additional funds raised will be used to sponsor further medical research about PHACES.

We are suggesting donations of \$25 per person or \$50 per family. Kids are definitely welcome! Please join us for a wonderful brunch to celebrate friends, good times, and (hopefully) great fall weather. And most important of all, please help us celebrate the life of our daughter Rachel and the contribution she is going to make to PHACES and the world.

If you are unable to join us please consider sending us a donation made payable to NOVA at 1234 Main Street, Anytown, USA, 12345.

Thank you for your generosity.
Janet, Andrew, & Rachel

PS: If you are interested in helping us raise funds and need an excuse for a party, please let us know. Visit <http://www.phaces.org> for more information.

At your event explain to Friends and Family how they can host an event too. Share your personal story of what NOVA has done for you and your family.

Once you have selected an event you will need to send out invitations like the one above. You may want to include a self addressed stamped envelope to allow people to send a donation if they can not attend.

**All Checks should be made payable to NOVA, on the memo line write
"Faces of PHACES"
All donations are 100% tax deductible**

National Organization of Vascular Anomalies

5. Record Keeping

Expenses/Reimbursement:

- As a host of an event you can give an in-kind donation to NOVA for all expenses you incur for hosting the event. YOU must have receipts. For example, if you spend \$100 on food and beverages, and you have a receipt. Your donation will be \$100. This is an in-kind donation and is 100% tax deductible.
- If you wish to request a reimbursement for your event expenses, that is ok as long as the amount refunded does not exceed 25% of what your event raised. For example if you raise \$1000.00 and the event food etc... cost you \$250.00 the \$250 will be reimbursed to you. You can not take a tax deduction on the \$250 and you must provide receipts to NOVA for the amount you are reimbursed.
- You will need to keep track of your event donations. Organizers of this campaign have created a form for you to use it can be downloaded at

http://www.phaces.org/pdf/Faces_of_PHACES_Donation_List.pdf

(see Attachment C)

- You should send out personal donation letters, thanking those who donated. NOVA will send out tax receipts and thank you notes to all donors of \$100 or more.

6. Planning Ideas:

- **How many people should I invite?** As many as you wish. You can create an intimate evening with just a few friends, or throw an all-out bash inviting everyone you know.
- **When should the event take place?** An event can be held at anytime. However, we would like to have as many events hosted by April 2008 as possible so that we can confirm the development of the PHACES conference in November 2008.
- **What is the admission charge?** Our goal is, together, to raise \$15,000 or more for NOVA. We recommend asking for a minimum donation of \$20 or \$25 per person. If you're having a family event, suggest a family donation of \$50 per family. Of course, we appreciate anything people can give and will accept any donation, no matter how small or large. The more people we invite, the more money we can raise for the kids!
- **Are donations tax deductible?** Definitely! All donations are 100% tax deductible, and donors who give \$100 or more will receive a thank you letter on NOVA letterhead for their tax files.

Donations can be made a couple of ways:

A check can be made payable to NOVA and should be collected by the host. The host should record this donation on the donation list and keep a copy of the list and mail the checks and list to NOVA c/o Roy Clemens 1571 Spring Road EXT Moon Township, PA 15108. All checks should be mailed within 30 days of events.

Cash: We suggest that the host collect all cash and send in one check to represent cash donations. The list of cash donations should be listed on the Donation List along with all other donations.

- ***What if someone can not attend my event?*** We know that not everyone you invite will be able to attend. Attendance is not required to make a donation. Encourage your friends, family, co-workers and neighbors to consider a donation even if they can not attend. Provide them with information on NOVA and PHACES.

6. Scheduled of Events: As of October 5, 2007 these events are planned.

10/2007 Roberts Raffle for Flat Screen TV in Boca Raton, FL Drawing 11/28/2007

10/2007 Jen's local wristband fundraiser, Canada- The Mighty Quinn

10/28/2007 Janey & Andrew's Brunch, Atlanta GA

11/2007 Wyndi & Steven Halloween Party, Seattle WA

11/14/2007 Ryans Birthday – donations in Lieu of Gifts

11/25/2007 Natalie & joe;s family reunion in Boca Raton Florida

1/12/2008 Wyndi and Steven Wedding place cared donations and "Dollar Dance with Bride or Groom campaign. Seattle WA

Spring 2008 Jen's Dinner hosted by Quinn

National Organization of Vascular Anomalies

8711-104 Six Forks Road

Raleigh, NC 27615

admin@mail.novanews.org

www.novanews.org

Attachment A Third Party Agreement



**National Organization
of Vascular Anomalies**

8711-104 Six Forks Road
PMB 126
Raleigh, NC 27615
www.novanews.org
admin@mail.novanews.org

BOARD OF DIRECTORS:
John DuBiel: President
Karla Hall: Executive Director
Lillian DuBiel: Treasurer
Robert W. Hall JR.
Kaye Mock, RN
Roy Clemens

MEDICAL DIRECTOR
Denise Adams, MD,

Fund Raising Policy and Third Party Donations

Working as partners with our patients and their families contributions are given to the organization. Families have collected money through creative methods. Bake Sales, letter drives and raffles. In keeping with good fiscal practices, the Board of Directors has developed guidelines pertaining to fund-raising events sponsored by individuals or organizations to benefit The National Organization of Vascular Anomalies. We request that all individuals or organizations wishing to host a fundraising event complete a Fundraising policy agreement.

In keeping with good operating and fiscal practices, the Board of Directors has developed the following guidelines pertaining to fundraising events sponsored by individuals or organizations to benefit NOVA

- All individuals or organizations wishing to host a fundraising event must complete a Fundraising Policy Agreement before the event/events.
- A member of the NOVA Board of Directors will telephone or visit with about any questions you may have and then confirm the event within 7 days of receiving the policy agreement.
- All proceeds and a final income/expense report need to be submitted to NOVA within 30 days following the event.
- A separate Bank account in the name of NOVA cannot be opened in conjunction with any fundraising event. All Checks are to be made payable to NOVA

Please complete the following questions to assist you in planning your fundraising event.

Coordinator/Contact Person _____ Date _____

Address _____ City _____ State _____

Zip _____ Email _____ Phone _____

Fax _____ other _____

Co-sponsor of event or other responsible person _____

Contact information for Co-sponsor of fundraising activity _____



Please describe the fundraising activity you are proposing to host for NOVA. Attach additional pages if necessary.



Have you determined a date for the fundraising activity? _____

Is this a single date event or will there be multiple days for the activity? _____

Event date _____ Event time _____

Event Location _____

Will any alcohol beverages be served? _____ ** permit required _____

If yes, date obtained _____ A copy of this permit must be attached to the agreement.

Is Insurance required for this event? _____ liability _____ property

What insurance company will be used? _____

Policy Number _____

Is Admission charged? _____ If yes amount _____

Complimentary Admission given to anyone _____ whom _____

Expected Cost of event _____ Please attach a copy of a budget for the event if you have one.

Will you expect NOVA to reimburse you for expenses related to hosting the event? _____

Will you donate the expenses to NOVA as a tax deductible donation to the organization? _____

How is the event being promoted?

Will you sell tickets to the event/events? _____

Will you use Pay Pal? _____

What is the major source of funds being raised _____ Admission _____ Entry Fee
_____ Auction
_____ donations _____ sponsor/pledges _____ sales _____ raffle, drawing, etc..

Other _____



Anticipated Income\$ _____ Anticipated Expenses\$ _____

Anticipated Net Profit\$ _____ % of Net Profit to be donated to NOVA _____ %

If less than 100% you must state the respective percentage on all promotional materials.

Will the event benefit another organization _____yes _____no

If yes please provide the name of the other organization (s) to be benefited by this event/events

If yes please attach a copy of a ticket or other promotional material highlighting donation % and organizations benefiting if applicable.

How long have you put on this type of benefit _____first year _____-years

How often will this event occur? _____annually _____single event

other _____

If required have ticket sales been cleared by local government _____

Would you like assistance from NOVA for this event? _____

Explain type of assistance needed _____

Will you require the use of the NOVA Logo _____ If yes how and when will it be used _____

Would you like your event information to be published in the newsletter, web-site, message board or media _____

Clarify _____

I understand that by agreeing to publish this information, I release NOVA from any liability due to risk of exposure. _____

Do you want the money raised from this event to be restricted to a specific area of NOVA, example research grants, conferences, family assistance. Please specify. _____



Please write the announcement you would like us to use in our Newsletter or on our web site. If you have a web site for the event please provide URL so we can link directly to the site.

Please provide any additional information about the fundraising proposal that you want NOVA to consider when authorizing the proposed fundraising activity.

Signature of Fundraising Coordinator _____
Date

Please Print Name of Fundraising Coordinator

Signature of Fundraising Co-sponsor _____
Date

Please Print Name of Fundraising Co-sponsor

Please return signed proposal to Karla Hall NOVA PO Box 0358 Findlay, OH 45840 admin@mail.novanews.org
Retain a copy for your records

| |
|---|
| <p>Administrative Use Only</p> <p>Date Received in office _____</p> <p>Date Reviewed by Board of Directors _____</p> <p>Changes/ Addendums _____</p> <p>_____</p> |
|---|



The National Organization of Vascular Anomalies Policy Agreement and Guidelines

The NOVA Board of Directors is pleased to be selected as a beneficiary of your volunteer time and financial support through fundraising programs, projects and events. However; in order to protect you, your volunteers and NOVA we require:

1. Completion and return of this agreement form for review and consideration to conduct any event or to appeal to the public in anyway. We prefer this be submitted 30 days prior to the event date and welcome your telephone calls to discuss this event.
2. Use of the Name, NOVA, its logo or any other term implying endorsement or support of NOVA is not authorized except by the confirmed returned approval agreement.
3. There will be due diligence on your part and to assist you on our part to have no conflict with government regulations, licensing and you agree to obtain all required insurance, permits or licenses.
4. The Executive Director of NOVA must review materials prior to use or any form of commercialism.
5. We respect our families and require there be no inadvertent exploitation of children, adults or parents in connection with this event, including but not limited to photographs or video. NOVA has a consent form to be signed by individuals featured in any photos or video used for solicitation during the event. This form must be signed by the individual, parent or guardian and returned to NOVA. A copy of the photo or video must be provided to NOVA.
6. Advance approval is necessary for any reproduction of the logo or name before printing or releasing to the media.
7. You understand that NOVA assumes no responsibility for promoting the event nor will the organization cover any financial losses associated with the event.
8. The event sponsor, organizer, organization hosting the event intended to benefit NOVA agrees to indemnify, defend and hold NOVA harmless against and in respect of any and all claims, demands, losses, costs, expenses, obligations, liabilities, damages, recoveries and deficiencies, including interest, penalties, reasonable attorney's fees that shall be incurred or suffered by NOVA which arise, result or relate to applicants fundraising event or program, applicants performance of its agreement as specified in these guidelines and the Fundraising Event form.
9. If a professional fundraiser or promotion person is hired to coordinate the event that benefits NOVA, please notify NOVA immediately. I (we) agree to adhere to all federal, local and state laws and assure that compensation to any professional shall NOT be based on commission or percentage of monies raised.
10. The Executive Director will review your requests for NOVA assistance to ensure efficient organization productivity.
11. Additionally, I (we) agree to submit to NOVA the name of any national corporation or business solicited for support in advance to avoid any conflict of interest with sponsors and donors who may already be involved with other fundraising efforts benefiting NOVA.
12. Within 30 days of the completion of the scheduled event all net proceeds will be delivered to **NOVA 8711-104 Six Forks Road PMB 126 NC 27615.**

I (we) herby affirm the information provided on the NOVA Third Party Fundraising Policy & Proposal and any attachments or addendums is true to the best of my (our) knowledge. I (we) understand the fundraising guidelines and agree to them in entirety.

Name (s) _____

Signature (s) _____

Date _____

NOVA has reviewed this application and signed guidelines and grants permission for this group to use its name for the specified fundraising event.

Authorized Signature _____ Date _____

Seal

Please complete a copy of this agreement for your records and return original to NOVA. If you have any questions please contact Karla Hall NOVA PO Box 0358 Findlay, OH 45840 admin@mail.novanews.org

Attachment B Donation Records

We Need Your Help

The Mission of NOVA is to assist individuals and their families in the management of vascular anomalies.

In order for NOVA to provide assistance to those in need we need your financial support.

As an all volunteer organization 100% of the donations we receive is used for the operation of the organization, serving those affected by hemangioma and vascular malformation.



Send your tax deductible donation to

The National Organization of Vascular Anomalies.

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NOVA Board of Directors

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Denise Adams, MD, Medical Director
Lillian DuBiel– Treasurer
Robert W. Hall– Secretary
Kaye Mock
Roy Clemens

Family Support Advocates

Jodi Salley
Carol Colombo
Jennifer Duncan

NOVA Physician Advisors

Sherry Bayliff, MD Lexington, KT
Francine Blei, MD New York, NY
Lisa Buckmiller, MD Little Rock, AR
Patricia Burrows, MD New York, NY
M. Sean Freeman, MD Charlotte, NC
Marcelo Hochman, MD, Charleston, SC
Ilona Frieden, MD, San Francisco, CA
John Gregory, MD, Morristown, NJ
George Haney, MD Cincinnati, OH
Denise Metry, MD, Houston, TX
Martin Mihm, MD Boston, MA
John Mulliken, MD, Boston, MA
John Reinisch, MD, Los Angeles, CA
Milton Waner, MD, New York, NY
Barry Zide, MD, New York, NY

Scientific Advisors:

Carmen Barnes, PhD Boston, MA
Doug Marchuk, PhD Durham, NC
Paula North, MD, PhD Milwaukee, WI



Providing information on the diagnosis and treatment of hemangioma and vascular anomalies

The National Organization of Vascular Anomalies



**Vascular Anomalies...
More Than a Birthmark**

Hemangioma

Hemangioma is the most common benign tumor of infancy and children. Most are not evident at birth but develop in the first weeks of life. Hemangiomas occur in 5-10% of all children and are 3-5 times more common in females than males. Hemangioma can occur any where on the

body however; most occur in the head and neck region.



Hemangioma can occur any where on the body.

Hemangiomas occur more often in Caucasian infants than African American or Asian infants. A hemangioma may grow for the first 8-12 months of life. The

Growth phase can be prolific and may appear to change daily. A hemangioma may begin to regress spontaneously at around 1 year of age. This involution phase may take several years and may leave residual scarring.

Vascular Malformations

Vascular Malformations are abnormally developed vessels. Vascular Malformations can exist in the veins, arteries, capillaries or lymphatic vessels. Vascular Malformations are always present at birth but may not become evident until later in life. Vascular Malformations do not spontaneously regress. Vascular Malformations grow through out an individuals life.

Complications

Hemangioma

During the growth phase of a hemangioma, the tumor can cause complications including, bleeding, pain, ulceration, and infection. Hemangioma can interfere with major organ structure, obstructing vision, breathing and they can interfere with feeding. Hemangioma can occur externally or internally.



Hemangioma can interfere with major organ structures.

Vascular Malformations

Vascular Malformations can be localized or diffuse. They can affect veins, capillaries, arteries and lymphatic vessels. The mass they form can cause significant pain and disfigurement. They can interfere with major organ structures, interfering with breathing, limb function and vision.

Vascular Malformations are often first diagnosed as a hemangioma. This leads to frustration for the patient and family of those affected. Often individuals learn as adults they have a vascular malformation

Both Hemangioma and Vascular Malformations are associated with medical disorders. Individuals should be carefully



evaluated by a physician experienced in the management of Vascular Anomalies.

Many adults are first diagnosed with hemangioma. Only to learn they have a vascular malformation.

The National Organization of Vascular Anomalies

The National Organization of Vascular Anomalies provides assistance to those affected by hemangioma, vascular malformation, PHACES, PWS, SWS, KT, KHE, Tufted Angioma and other benign vascular tumors.

Nova provides the following services:

Educational Materials & Resources

Medical Conferences

Patient Advocacy

Patient Support

insurance Education & Assistance

Web page & message board

Physician Networking

Networks with other charities

Medical Research

Charitable Grants/Assistance

For More Information visit the NOVA website

www.novanews.org

or email admin@mail.novanews.org

NOVA provides this information as a resource. It is not intended to engage in the practice of medicine or to replace the information provided by physicians. NOVA does not claim to have medical knowledge. NOVA does not endorse or promote any particular physician, treating facility or treatment. In all cases NOVA and its Board of Directors recommends that individuals seek the opinion of a physician experienced in the management of Vascular Anomalies.

We Need Your Help

The Mission of NOVA is to assist individuals and their families in the management of vascular anomalies.

In order for NOVA to provide assistance to those in need we need your financial support.

As an all volunteer organization 100% of the donations we receive is used for the operation of the organization, serving those affected PHACES and vascular anomalies.



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Lisa Buckmiller, MD Little Rock, AR
Patricia Burrows, MD New York, NY
Marcelo Hochman, MD, Charleston, SC
Steven Fishman, MD, Boston, MA
Ilona Frieden, MD San Francisco, CA
John Gregory, MD, Morristown, NJ
Denise Metry, MD, Houston, TX
Martin Mihm, MD Boston, MA
John Mulliken, MD, Boston, MA
John Reinisch, MD, Los Angeles, CA
Milton Waner, MD, New York, NY
Barry Zide, MD, New York, NY

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Carmen Barnes, PhD Boston, MA
Doug Marchuk, PhD Durham, NC
Paula North, MD, PhD, Milwaukee, WI



Providing information on the diagnosis and treatment of vascular anomalies

The National Organization of Vascular Anomalies



PHACES an association of symptoms

PHACES...

PHACES is the uncommon association between large infantile hemangioma, usually of the face and birth defects of the brain heart eyes or skin.

P– Posterior Fossa Abnormalities and other structural brain abnormalities

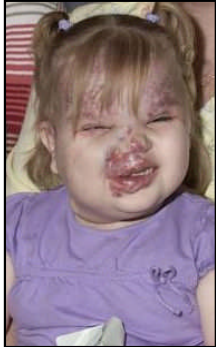
H– Hemangioma of the cervicofacial region

A– Arterial Cerebrovascular Anomalies

C– Cardiac Defects & co-arcuation/other aortic abnormalities

E– Eye Anomalies

S– Sternal defects and or supra-umbilical raphe



Both the presentation and the severity of the symptoms vary greatly in PHACES.

The association of symptoms has a greater incidence in females.

The exact cause is unknown, there is currently no means of prevention.

90% of PHACES patients present with a facial hemangioma.

Management

Patients presenting with hemangioma of the head and neck should be evaluated by a Vascular Anomalies Center or physician experienced in the management of PHACES.

Diagnosis / Treatment

NOVA can assist you in finding a treatment center.

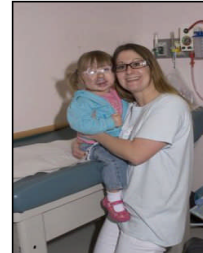
Many diagnostic tests can be performed at these centers to help determine the extent of PHACES.

- **MRI/MRA**
- **Ultrasound**
- **Angiography**
- **Echocardiogram**
- **Ophthalmologic Exam**
- **Endoscopy**

Depending on which symptoms a patient presents with the physicians will determine the best treatment available.

Treatment plans are designed to manage the most serious complications and to prevent further complications from developing.

A patient registry has been established, NOVA can assist you in registering for the PHACES patient registry.



PHACES is best managed in a multi-disciplinary clinical Setting.



NOVA offers family conferences allowing those affected by PHACES to meet each other and consult with leading physicians in the field.

The National Organization of Vascular Anomalies & PHACES

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- **Medical Conferences**
- **Patient Advocacy**
- **Patient Support**
- **Insurance Education & Assistance**
- **Web page & message board**
- **Physician Networking**
- **Networking with other charities**
- **Medical Research/Registries**
- **Charitable Grants/Assistance**

NOVA directs much of its efforts toward the education, advocacy and support of those affected by Vascular Anomalies. PHACES is a large focus of our efforts.

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