

phace syndrome™  
community



# PSC YEAR ONE

## What we have accomplished:

- **Amazing Logo**
- **Beautiful Website**
- **Our first official speaking engagement at PeDRA**
- **International PHACE Syndrome Awareness Week**
- **2014 Family Conference**
- **PSC Brochure**
- **Approaching 200 members on our Facebook group / Community**
- **Positive Exposure Partnership / Rick Guidotti**
- **Long term organization strategy**

# OUR MISSION

**PSC's mission as mentioned in our Bylaws is as follows:**

- To create a community where families and individuals affected by PHACE Syndrome, along with their supporters, are able to obtain links to diagnostic and treatment information, ranging from early diagnosis to daily concerns
- To cultivate/accelerate awareness and education of PHACE Syndrome
- To support research in order to determine the cause of PHACE Syndrome
- To enhance and improve treatment of PHACE Syndrome AND to aid in preventing complications related to PHACE Syndrome AND to aid in the prevention of PHACE Syndrome

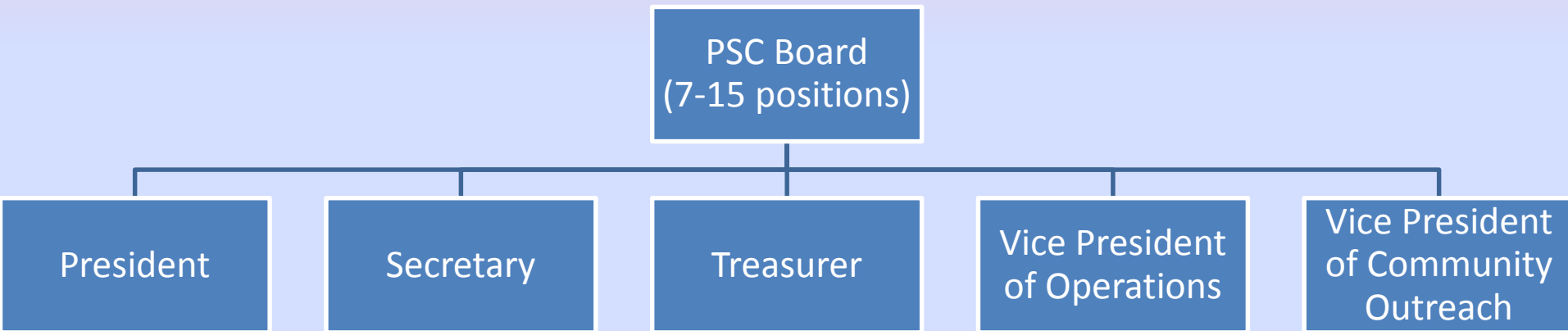
# ORGANIZATION SUMMARY

## BOARD OF DIRECTORS

- The Board runs and oversees the organization. Since the organization is small and new, the Board is a “Working Board” meaning individual Board members usually take on specific roles, projects, and tasks.
- General requirements for a Board Member.
  - Attend via phone 1 to 2 (currently 2) board meetings per month - working session + the monthly board meeting 9-10 Eastern time 1st and 3rd Thursday of the month
  - Attend via phone officer meetings as necessary - probably 1-2 per month - usually 8:30 or 9:00 Eastern time, no set dates
  - Attend via phone committee meetings as necessary - usually 1-2 per month
  - Be a willing source of help with ideas and the execution of current tasks
  - Attend the PHACE Family Conference and the board meeting to be held prior to the conference

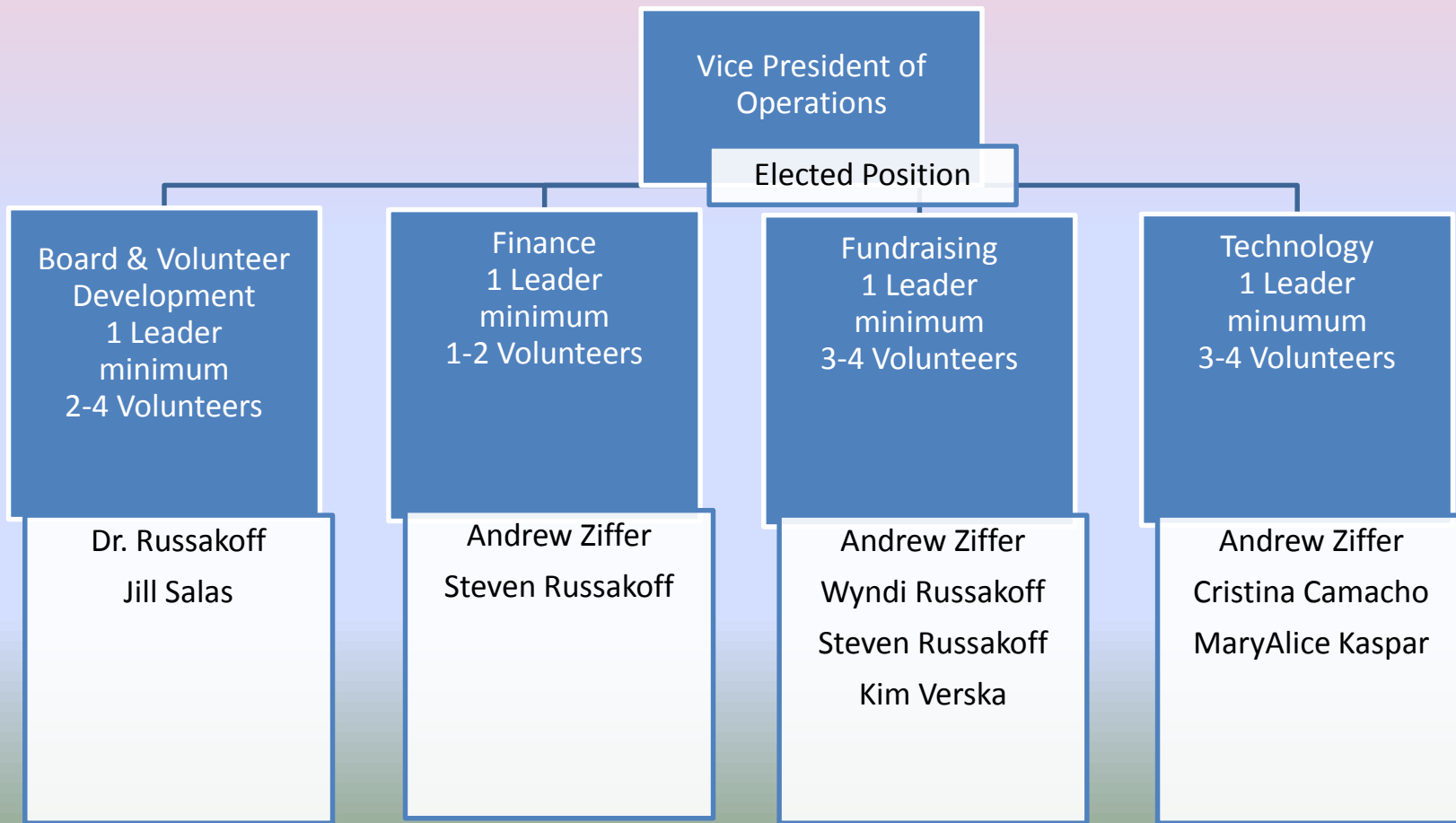
# ORGANIZATION SUMMARY

- Officers that report to the Board include below
- These positions are elected by the Board yearly
- Prefer a committee contribution before joining the Board



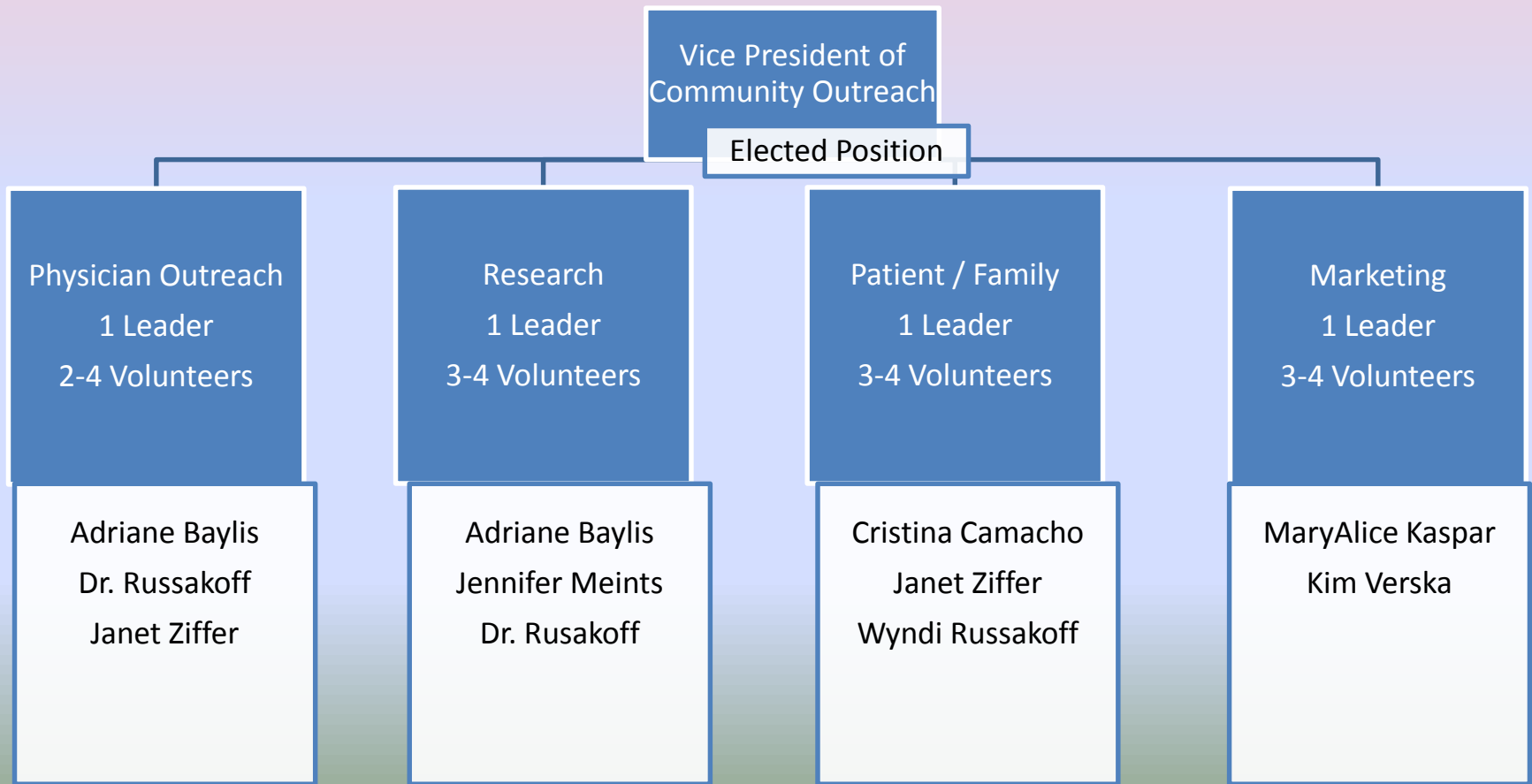
# ORGANIZATION SUMMARY

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- To accomplish our goals, fully staffed Board and Committees will look as follows:



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- To accomplish our goals, fully staffed Board and Committees will look as follows:



# ORGANIZATION SUMMARY

- **President**
- **Vice President of Operations**
  - Board & Volunteer Development Committee (1 lead and 2 to 4 persons)
  - Finance Committee (1 lead and 1 to 2 persons)
  - Fundraising Committee (1 lead and 3 to 4 persons)
  - Technology Committee (1 lead and 3 to 4 persons)
- **Vice President of Community Outreach**
  - Physician Outreach Committee (1 lead and 2 to 4 persons)
  - Research Planning and Participation Committee (1 lead and 3 to 4 persons)
  - Patient/Family Programs Committee (1 lead and 3 to 4 persons)
  - Marketing Committee (1 lead and 3 to 4 persons)
- **Treasurer**
- **Secretary**

It is possible that one person may take on multiple roles and responsibilities. The VP in charge of the group will be responsible for monitoring the progress and function of the Committees.



# ORGANIZATION SUMMARY

## PRESIDENT

- The President oversees the entire organization and is responsible for carrying forward the Board's Direction. The President is also the "Face of PHACE" so it will be important for this person to be very familiar with PHACE Syndrome.

# ORGANIZATION SUMMARY

## VICE PRESIDENT OF OPERATIONS

- The Vice President of Operations manages and oversees the day to day activities of administering, running, and building the organization. This is the internal role that manages the smooth and successful operations of what supports our ability to run and thrive in the outside world.
- The Vice President of Operations also serves as the President should she/he be unavailable.

# V.P. of OPERATIONS

## BOARD & VOLUNTEER DEVELOPMENT COMMITTEE

1 LEAD AND 1 TO 2 PERSONS

This committee plans and monitors Board roll on and roll off and is also responsible for engaging the community to find able bodies willing to help us support the organization and its mission.

Specific tasks include:

- Managing new Board Members education and integration into our culture and processes
- Ensuring the Board is staffed appropriately as Board members complete terms
- Developing a volunteer program and a pool of willing and able volunteers

# V.P. of OPERATIONS

## FINANCE COMMITTEE

1 LEAD AND 1 TO 2 PERSONS

This committee is responsible, along with the treasurer, for maintaining a valid and correct copy of our finances, probably in QuickBooks as it is today. This committee is also responsible for complete transparency to the Board regarding the financial position of the organization. Other specific tasks include:

- Filing an annual tax return with the IRS
- Filing and annual registration with the State of Georgia to keep our corporation active and compliant
- Distributing thank you letters for donations above \$50
- Documenting approved expenses and writing checks
  - A majority officer vote may approve amounts less than \$250
  - A majority Board vote must approve amounts above \$250

# V.P. of OPERATIONS

## FUNDRAISING COMMITTEE

1 LEAD AND 3 TO 4 PERSONS

- The financial wellbeing and thriving of the organization will always depend on our funding. A specific role will support this function to plan and execute our fundraisers.
- Specific tasks include:
  - Developing a fundraising program so others can raise money
  - Keeping a pool of ideas for those who are willing to take on a fund raiser
  - Managing the process
  - Enrolling others in creating fund raisers
  - Developing the Race for PHACE

# V.P. of OPERATIONS

## TECHNOLOGY COMMITTEE

1 LEAD AND 3 TO 4 PERSONS

- This committee will support:
  - Website
  - ActiveBoard
  - Email distribution (Email and Community list will be supported by multiple groups – need to resolve how this works)

# ORGANIZATION SUMMARY

## VICE PRESIDENT OF COMMUNITY OUTREACH

- As the role suggests, this is the outward facing support position of our organization. They are responsible for managing all aspects of the way our organization interacts with the PHACE Community and the rest of the world.
- The Vice President of Community Outreach also serves as the President should the President and Vice President of Operations be unavailable.

# V.P. of COMMUNITY OUTREACH

## PHYSICIAN OUTREACH COMMITTEE

1 LEAD AND 2 TO 4 PERSONS

Responsibilities of this Committee include:

- Formation and support of the Medical Advisory Board
- Maintaining doctor database published on website (content only – Tech group will publish on web)



# V.P. of COMMUNITY OUTREACH

## RESEARCH PLANNING AND PARTICIPATION COMMITTEE

1 LEAD AND 2 TO 4 PERSONS

Responsibilities of this Committee include:

- Determine priorities of programs needed to help those affected with PHACE
- Determine where research funds should be dedicated
- Identifying and applying for appropriate grants
- Encourage and facilitate participation in current and future research programs – i.e. The PHACE Registry

# V.P. of COMMUNITY OUTREACH

## PATIENT/FAMILY PROGRAMS COMMITTEE

1 LEAD AND 3 TO 4 PERSONS

Responsibilities of this Committee include:

- PHACE Conference
- New member welcome and support process
- Family Newsletter
- Family Education
- Community Education
- Physician Education

# V.P. of COMMUNITY OUTREACH

## MARKETING COMMITTEE

1 LEAD AND 3 TO 4 PERSONS

Responsibilities of this Committee include:

- Public Newsletter & Communication

Other ideas include how we market ourselves and what opportunities do/will we have - PeDRA, NORD, Coalition of Skin Disease, Pierre Fabre.

# ONGOING SUPPORT ACTIVITIES

## PSC will support the following activities:

- Creating a friendly, warm, and cooperative community
  - Enabling PHACE families to get the information they need
  - Letting them know “they are not alone”
  - Providing helpful, healthy (an “ear”) support for those dealing with issues related to PHACE
- Website maintenance
- Facebook Community
- ActiveBoard Community
- Regular Newsletter (beginning post conference)
- Community member list
- PHACE Conference (how often do we have it?)

# LONG TERM PROJECTS

PSC long term goals which we would like to focus on in the next year include:

- Medical Advisory Board
- Research Needs and Priorities
- Funding Projects and Research
- Membership Program

After Conference Survey for 2014 should set the priorities and start of this conversation.

# LONG TERM PROJECTS

## MEDICAL ADVISORY BOARD

The Medical Advisory Board provides guidance and leadership to the organization on all medical issues relative to PHACE Syndrome.

The Medical Advisory Board promotes access to quality care by advocating for better clinical research, promoting medical education, and assisting with the development of information relating to PHACE Syndrome.

Duties could include:

- Review the PSC website and other communications for medical accuracy.
- Make recommendations regarding medical research grants when research funding is available.
- Promote communication among the Public and International medical community in regards to PHACE Syndrome.
- Provide referrals/recommendations to PHACE patients as the need arises (not medical advice from PSC).

Specialties to consider - Cardiology, Dermatology, ENT, Plastic Surgery, Ophthalmology, Neurology, Neurointerventional Radiology, Peds Nurse(RN), Pediatrician, Vascular Anomalies Specialist

# LONG TERM PROJECTS

## RESEARCH NEEDS AND PRIORITIES

The Medical Advisory Board and PSC can jointly determine priorities around:

- Research needed
- Projects to support patients
- Sharing of trends around PHACE treatment
- Education
- Conferences

# LONG TERM PROJECTS

## FUNDING PROJECTS AND RESEARCH

- Research and other projects will need funding. Once these projects are defined, we can start the process to fund, including paths such as:
- Board fundraisers
  - Board members
- Community membership
- Community fundraisers
  - Race for PHACE
  - T-Shirts
  - Dinners
  - Individual fundraisers
- Public and Private Grants
- Other creative options



# LONG TERM PROJECTS

## CONTINUING SUPPORT PROGRAM

Develop a formal community donor or supporting community membership program to enable long term participation in the community and sustainability for the Organization. This may also be considered a component of fundraising. While we will never exclude anyone from the community, this program will be one way the surrounding community can help support us on a regular basis.

# HOW CAN YOU HELP?

- TIME – Via a committee
- AWARENESS – International PHACE Syndrome Awareness week
- RESOURCES – Via \$\$\$ OR fundraisers
- RACE FOR PHACE – In your City

WHERE DO YOU SEE YOURSELF IN THE  
COMMUNITY?

**THANK YOU!**

**We would love to receive your feedback!**

**Please take a moment to fill out our survey.  
Come join us and help make a difference, your  
time would be greatly appreciated by more  
people than you could ever imagine!!**