

# WELCOME TO PANS RESEARCH AND ADVOCACY INITIATIVE

Dear Volunteer:

Hello, and welcome to PANS Research and Advocacy Initiative (PRAI). We are a 501c3 nonprofit group of parents, healthcare workers and other members of the community committed to making a positive change by addressing a devastating condition affecting thousands of children called PANDAS or PANS.

PANDAS stands for pediatric autoimmune neuropsychiatric disorder caused by strep. Similarly, PANS stands for Pediatric acute onset neuropsychiatric syndrome. Some symptoms include OCD, Tics, Anxiety, Bed-wetting, ADHD, joint pain, emotional lability, aggression and oppositional defiant behaviors. According to the National Institute of Mental Health as much as 25-35% of all pediatric mental illness may be prevented with early diagnosis and proper treatment of PANDAS/PANS. That means we have a big and important job to do.

It takes a lot of hard work and a great group of dedicated people to get it done. That's where you as a volunteer come in! Consider yourself the backbone of PRAI and the force that brings our dream to reality. We cannot do this without you! Please familiarize yourself with our mission because everything we have done and continue to do flows out from it. We look forward to a long lasting partnership with you.

We are forever grateful for your time, energy and support. Now let's get PANDAS/PANS the attention it deserves from insurance companies, researchers, and the medical community.

- PRAI Board of Directors

## MISSION STATEMENT

PRAI is an organization advocating on behalf of families who suffer from pediatric autoimmune neuropsychiatric syndromes by providing emotional and social support, investing in data-driven research and education, and raising awareness in the community.

## VISION

PRAI envisions a world where research provides an effective treatment for PANDAS/PANS allowing all our children to grow and thrive, and where families no longer suffer from this debilitating condition.

## ORGANIZATIONAL GOALS

- Increase awareness of PANS/PANDAS among parents, physicians and the community
- Provide information and support to families suffering from PANS/PANDAS
- Educate pediatricians and parents on treatment protocols
- Raise funding for research for PANS/PANDAS
- Support legislation for PANS/PANDAS awareness and research

## PRAI VOLUNTEER PHILOSOPHY

- All who share a commitment to our mission are welcome to join us in our work regardless of their background, ethnic origin, race, age or gender. Everyone is welcome at our table.
- PRAI is inclusive and made up of a diverse group of individuals who put aside personal agendas, egos, and differences to support PRAI's mission.
- Every member of the PRAI family is valuable and everyone's time, talents, and efforts are special gifts that are to be appreciated, respected, recognized, and never taken for granted.
- The right role can be found for any person with a desire and heart to serve. Volunteers should be given opportunities to learn and grow within the organization.
- The work of every volunteer is valued equally. All volunteers are treated with dignity and respect.
- PRAI values volunteers by giving them meaningful work to do and the materials, tools, training, and supervision to complete their tasks safely and in a timely manner.
- Volunteers are responsible for the quality of their work, their conduct at PRAI work sites, and for meeting their commitment to PRAI, its families, and its mission.
- All volunteers deserve frequent and accurate information about PRAI activities and operations provided through regular, open, one-on-one communication through publications, and through conversations with board members
- Volunteers provide our organization with credibility, insight, perspective, diversity, and expertise that enlightens our operations, helps fulfill our mission, and engages the community in our activities.

## TO IMPLEMENT THIS PHILOSOPHY, PRAI WILL:

- Actively seek and encourage participation of volunteers in all areas of the organization including planning, problem-solving, fundraising and administration.
- Share strategic and business plans and on-going schedules to inform volunteers and focus their energies.
- Respond to all inquiries from prospective volunteers in a timely manner to facilitate their orientation and scheduling.

- Match volunteers with tasks that meet their interests and skills, with clear instructions, deadlines, materials, tools, and freedom to complete the tasks.
- Foster personal growth among volunteers by providing skilled supervision, training, and opportunities to learn new skills.
- Train all volunteers and who are willing to learn.
- Give volunteers meaningful work and abundant thanks, directly and frequently.
- Consider all volunteer requests, suggestions, and grievances in a respectful and timely manner.
- Work together to continually renew and reinforce our mutual commitment to the mission of PRAI.

## LIST OF POSSIBLE VOLUNTEER TASKS

- Assisting at PRAI events
- Distributing PRAI material
- Calling or writing your legislators when needed
- Manning our help line
- Fundraising
- Creating information packets for families
- Launch and lead support groups
- Administrative tasks
- Working on social media
- Calling on media
- Networking in the community for partnerships
- Conducting PRAI information presentations in the community
- Sharing your story online
- Editing, Proofreading, creative writing services
- Supporting our Youth Awareness programs

## HARASSMENT AND DISCRIMINATION

- PRAI is firmly committed to providing a positive work environment free of discrimination and bias. Each volunteer is personally responsible for maintaining such a work environment.
- PRAI prohibits any actions, words, jokes, or comments based on an individual's race, sex, sexual preferences, ethnic background, age, religion, physical condition, or other legally protected characteristic. Any conduct or action, whether overt or subtle, which creates an offensive or hostile work environment is prohibited and will be grounds for immediate disciplinary action.
- PRAI prohibits any harassment between volunteers, board members, or other non-employee on the basis of sex. No volunteer, male or female, should be subjected to unsolicited or unwelcome sexual overtones and conduct, either verbal or physical. Misconduct applies to males and females, and includes harassment between individuals of both sexes and the same sex. Any volunteer who believes he or she is a victim of sexual or discriminatory harassment is encouraged to let the harasser know that his or her behavior is unwelcome. In addition, volunteers who believe they have been harassed must immediately report the matter to a board member. A grievance is then filed.

## PRAI VOLUNTEER CODE OF ETHICS

- Take your commitment to our organization to heart, performing your duties to the best of your ability.
- Never offer what can be interpreted as “medical advice”.
- Honor confidentiality.
- Respect the mission and goals of PRAI.
- Dress appropriately
- Do not speak or otherwise engage in media discussion without direct approval of either the President or Vice-President of PRAI
- Deal with conflicts or difficulties in an appropriate manner as outlined in this manual.
- Respect the property of PRAI.
- Do not accept valuable gifts or money from families.
- Never offer what can be interpreted as “medical advice”.
- Be courteous, friendly and cooperative.
- Offer constructive feedback about our organization in an appropriate manner.
- The use of alcohol or drugs while conducting or representing PRAI is strictly prohibited.
- Be willing to learn and take part in orientation and training sessions.
- Follow through on commitments and advise a board member if you need further clarification or assistance.

**Note:** PRAI is an at-will organization and has the right to terminate a volunteer without cause, but will always consider the cause leading to the termination.

## GRIEVANCES

Under this policy, a grievance is defined as any event, condition, rule, or practice which the volunteer believes violates his or her civil rights, treats him or her unfairly, or causes him or her any degree of unpleasantness or unhappiness on the job. A grievance may also deal with an attitude, or an opinion or statement held by a staff member or fellow volunteer.

Volunteer grievances are of great concern to PRAI, regardless of whether the problem is large or small. To provide prompt and efficient evaluation of, and response to grievances, PRAI has established a procedure for all volunteers. It is PRAI's policy to give full consideration to every volunteer's opinion. There will be no discrimination against or toward anyone for his or her part in presenting a grievance. All grievances are handled confidentially.

THE GRIEVANCE PROCEDURE IS:

- 1) If urgent action is needed, notify the Board President or Vice-President immediately.
- 2) Attempt to discuss your grievance with a board member to work out the problem.
- 3) If you are unsatisfied, submit your complaint in writing to the Board President or Vice-President.
- 4) A response should be made within 5 business days.
- 5) If you are not satisfied within 5 days of how your written complaint was handled, you may appeal by submitting your written complaint to the full board.
- 6) The Board should respond within 5 business days. The Board's decision is final.