

Strategic Plan (2015-19)

Strategic planning is the process of determining what our organization intends to accomplish, and how we will direct the organization and its resources toward accomplishing our objectives over the coming months and years. This five-year strategic plan has been prepared to support the vision and mission of Prader-Willi Syndrome Association (USA) and will be accomplished through 12 focus areas. The annual business plan is to ensure implementation of the strategic plan.

Vision

Prader-Willi Syndrome Association (USA) will be a self-sustaining, internationally recognized leader, empowering those affected with Prader-Willi syndrome to enjoy a productive life in an informed and accepting community.

Mission Statement

PWSA (USA) is an organization of families and professionals working together to raise awareness, offer support, provide education and advocacy, and promote and fund research to enhance the quality of life of those affected by Prader-Willi syndrome.

Focus Areas

1. **Crisis Intervention and Support** (provide urgent and preventive services)
2. **Fund Development** (identify and provide sustainable funding for PWSA (USA))
3. **Awareness** (provide knowledge of PWS and PWSA (USA))
4. **Research** (inquire and investigate into the causes, treatments and effects of the syndrome)
5. **Medical Intervention and Support** (respond, educate and share medical issues)
6. **Education** (instruct and development of knowledge)
7. **New Diagnosis Support** (mentor parents)
8. **Advocacy** (support for an idea or cause)
9. **Chapter, Affiliate and Local Support** (develop, strengthen and nurture local communities)
10. **National Conferences** (provide a forum for families and professionals to exchange information)
11. **External Collaborative Relationships** (work with external stakeholders)
12. **Administration** (provide an effective and efficient management of the Association)

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1. Focus Area: **Crisis Intervention and Support**

1.1. Goal: PWSA (USA) maintains a crisis counseling system that provides support and assistance for families experiencing urgent and preventive needs and experiencing difficulties obtaining services.

1.1.1. Objective: Build capacity with the state chapters with the goal of families and teams receiving support and assistance in their communities.

1.1.1.1. Action Step: Educate, support, and promote state chapter representatives as resources to their local families and teams, through networking at national, state, and local conferences and chapter meetings, and informally as needed.

Accountability: PWSA (USA) Extended Crisis Team

Due Date: On-going, with a focus a minimum of three chapters each year of the strategic plan.

Cost: Not to exceed \$3000 annually for travel and \$2000 for meeting expenses and publications beginning in 2016.

1.1.1.2. Action Step: Make every effort to attend and present at chapter leader's meetings, when requested.

Accountability: PWSA (USA) Extended Crisis Team

Due Date: At least one every year and upon request.

Cost: Chapter expense, when possible

1.1.2. Objective: Review available, relevant publications and other resources to assess whether what is currently available is sufficient to address the needs generally expressed by the crisis callers.

1.1.2.1. Action Step: Develop and maintain an internal process to review the publications currently available and to assess if they meet the needs of the membership, based on calls, requests, inquiries, etc.

Accountability: PWSA (USA) Crisis Team

Due Date: Prior to the first in-person Board meeting of each year

Cost: Indirect staff time

1.1.2.2. Action Step: Communicate and collaborate with the chairperson(s) of the Publications Committee to renew widely used documents and to discuss unmet publication needs.

Accountability: PWSA (USA) Crisis Team Leader (or his/her designee)

Due Date: Prior to the April in-person Board meeting of each year

Cost: As determined by budget

1.1.3. Objective: Develop and implement a method for measuring the effectiveness of the intervention(s) and supports provided by the Crisis Team member.

1.1.3.1. Action Step: Develop and/or identify a tool by which the effectiveness of the interventions presented can be assessed.

Accountability: PWSA (USA) Crisis Team Leader and his/her supervisor

Due Date: March 31, 2015

Cost: Indirect staff time

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- 1.1.4. **Objective:** Assure that the contacts that are made by families and teams for new parents, prevention strategies, and crisis responses result in an ongoing relationship and in a broadened, strengthened membership.
- 1.1.4.1. **Action Step:** Implement an in-house system by which any inquiries made through a Crisis Team member will receive a follow-up call from a staff/volunteer towards securing complete contact information, acquiring membership, and engaging them in future activities of PWSA (USA). Initial follow-up outreach within 14 days of first inquiry.
Accountability: PWSA (USA) staff
Due Date: April 30, 2015
Cost: Indirect staff time
- 1.1.5. **Objective:** Recognize that data collected through the Crisis program may be valuable to the Research Committee, and will provide information to the Committee as to the type of crisis inquiries received for the Committee's consideration.
- 1.1.5.1. **Action Step:** Review issues of crisis that may be relevant for the Committee's consideration as to what requests to fund at least two times each year, and in advance of the Research Committee's RFP deadlines.
Accountability: Crisis Team Leader, Research Committee Chair(s)
Due Date: Prior to each in-person Board meeting
Cost: Indirect staff time
- 1.1.6. **Objective:** Create and maintain teams of experts (medical, legal, family, school, residential placement, service obtainment) to serve as resources for crisis situations.
- 1.1.6.1. **Action Step:** Identify, support, and nurture a team of experts who can be available to advise in general policy and approaches, as well as in specific situations.
Accountability: Crisis Team Leader, Medical Affairs Coordinator
Due Date: June 30, 2015 and ongoing; to be reviewed annually by the Crisis Team Leader
Cost: Indirect staff time
- 1.1.7. **Objective:** Provide a semi-annual report summary of the crises contacts in the past year, in detail that is both relevant to members of the Board of Directors and the Clinical Advisory Board (CAB).
- 1.1.7.1. **Action Step:** Prepare and present information of the types and frequencies of crisis contacts to the Board of Directors, in advance of the semi-annual in person Board meetings.
Accountability: Crisis Team Leader, his/her supervisor
Due Date: Twice per year at in person Board meetings
Cost: Indirect staff time

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- 1.1.7.2. **Action Step:** Prepare and forward information regarding the types and frequencies of crisis contacts that are relevant to the work of the CAB in advance of CAB meetings and/or as requested by the CAB Chair.
Accountability: Crisis Team Leader, his/her supervisor, Director of Medical Affairs
Due Date: Prior to each CAB meeting and/or as requested by CAB Chairperson.
Cost: Indirect staff time
- 1.1.8. **Objective:** Provide initial and ongoing training opportunities for the Crisis Counselors.
- 1.1.8.1. **Action Step:** Provide on-boarding training and initial in servicing related to all PWSA (USA) policies, practices, and procedures, in addition to PWS specific base knowledge to all employees/volunteers under his/her supervision.
Accountability: Crisis Team Leader
Due Date: Upon hire of Crisis Team staff
Cost: Indirect staff time
- 1.1.8.2. **Action Step:** Provide ongoing training to his/her staff in the form of support, staff meetings, and opportunities for applicable training outside of PWSA (USA).
Accountability: Crisis Team Leader, his/her supervisor
Due Date: On-going and as outside opportunities present
Cost: Up to \$2000 annually
- 1.1.8.3. **Action Step:** Coach, train, and evaluate his/her staff to assure growth in the areas of core competencies as outlined in the job description.
Accountability: Crisis Team Leader, his/her supervisor
Due Date: On-going, formal evaluation at least annually
Cost: Indirect staff time

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2. Focus Area: **Fund Development**

2.1. Goal: Ensure (structurally) the long-term sustainable financial support for PWSA (USA) and its programs.

2.1.1. **Objective:** Develop a comprehensive organizational Case Statement (“who we are, what we do, and why you should support us”).

2.1.1.1. **Action Step:** Research and write a PWSA (USA) Fund Development Case Statement.

Accountability: Development Director

Due Date: January 31, 2015

Cost: Indirect staff time

2.1.1.2. **Action Step:** Review and update the Case Statement annually.

Accountability: Development Director

Due Date: Annually in October

Cost: Indirect staff time

2.1.2. **Objective:** Develop a multi-year Development Plan to support projected organizational growth, program needs, and research.

2.1.2.1. **Action Step:** Identify long terms program cost projections.

Accountability: Executive Director, Development Director and Finance Committee, Treasurer

Due Date: April 1, 2015

Cost: Indirect staff time

2.1.2.2. **Action Step:** Review and update the Development Plan annually.

Accountability: Development Director and Fund Development Committee

Due Date: Annually in October

Cost: Indirect staff time

2.1.3. **Objective:** Prepare an annual detailed Development Plan to support anticipated organizational growth, program needs, and research.

2.1.3.1. **Action Step:** Research and prepare a written evaluation of previous year development strategies and campaigns.

Accountability: Development Director and Staff

Due Date: Annually by January 31

Cost: Indirect staff time

2.1.3.2. **Action Step:** Prepare an annual Fund Development Report.

Accountability: Development Director and Staff

Due Date: For Spring Board meeting

Cost: Indirect staff time

2.1.3.3. **Action Step:** Set annual projected fundraising targets, by category.

Accountability: Development Director and Staff

Due Date: Annually in September

Cost: Indirect staff time

2.1.3.4. **Action Step:** Prepare an annual written Development Plan.

Accountability: Development Director and Staff

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Due Date: Annually by November 1 for coming year

Cost: Indirect staff time

2.1.4. **Objective:** Identify and establish priority for developing new (or not used in recent years) fundraising strategies that will contribute to long-term sustainable financial support for PWSA (USA).

2.1.4.1. **Action Step:** Implement annual goals and strategies for the procurement of grants.

Accountability: Development Director with Fund Development Committee

Due Date: On-going

Cost: Indirect staff time

2.1.5. **Objective:** Ensure appropriate staffing levels to meet the organization's Fund Development needs.

2.1.5.1. **Action Step:** Conduct annual review of staffing needs for Fund Development.

Accountability: Executive Director

Due Date: On-going

Cost: Indirect staff time

2.1.6. **Objective:** Establish policies, implement strategies and provide training to ensure that PWSA (USA) Fund Development practices meet best practice standards.

2.1.6.1. **Action Step:** Create Fund Development policies and procedures manual.

Accountability: Development Director

Due Date: May 15, 2015

Cost: \$500

2.1.6.2. **Action Step:** Define and establish accountability for each fundraising event and development strategy.

Accountability: Development Director

Due Date: May 31, 2015

Cost: Indirect staff time

2.1.6.3. **Action Step:** Implement a formal debriefing process with event planners and with staff accountable for each funding strategy as part of an annual evaluation of the Fund Development efforts of PWSA (USA).

Accountability: Development Director

Due Date: January 2016

Cost: Indirect staff time

2.2. Goal: Develop individual giving as a fundamental component in PWSA (USA)'s long-term financial sustainability.

2.2.1. **Objective:** Develop and implement a comprehensive Major Gift Program.

2.2.1.1. **Action Step:** Define Major Gift parameters and goals.

Accountability: Development Director

Due Date: January 2016

Cost: Indirect staff time

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- 2.2.1.2. **Action Step:** Prepare Major Gift packet; update annually.
Accountability: Development Director
Due Date: April 2016
Cost: \$2,500
 - 2.2.1.3. **Action Step:** Plan and implement Major Gift promotion and outreach.
Accountability: Development Director
Due Date: August 2016
Cost: \$2,500 annually
 - 2.2.2. **Objective:** Develop and implement a Planned Giving Program.
 - 2.2.2.1. **Action Step:** Prepare Planned Giving Packet; update annually, as needed.
Accountability: Development Director
Due Date: May 2016
Cost: \$1,500 annually
 - 2.2.2.2. **Action Step:** Plan and implement Planned Giving promotion and outreach.
Accountability: Development Director
Due Date: October 2016
Cost: \$3,000
 - 2.2.3. **Objective:** Increase income from the annual giving campaign (Angel Card).
 - 2.2.3.1. **Action Step:** Identify and implement strategies for strengthening the effectiveness and impact of the annual giving campaign.
Accountability: Development Director
Due Date: Fall 2015 and on-going
Cost: Indirect staff time
 - 2.2.3.2. **Action Step:** Develop and implement email, video and other online and social media strategies in support of the annual giving campaign.
Accountability: Development Director and Staff
Due Date: August 2015 and on-going
Cost: \$2,500 annually
 - 2.2.4. **Objective:** Strengthen promotion and follow up for employer matching gifts and employee engagement programs, such as, United Way and the Combined Federal Campaign.
 - 2.2.4.1. **Action Step:** Include regular reminders and short articles in the Gathered View and through other PWSA (USA) communications channels.
Accountability: Development Director and Staff
Due Date: January 2017 and on-going
Cost: Indirect staff time
- 2.3. Goal: Develop *On The Move (OTM)* as a signature fundraising campaign for PWSA (USA) by May 2015.**
- 2.3.1. **Objective:** Strengthen and expand the annual fundraising capacity of *OTM*.

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- 2.3.1.1. **Action Step:** Reach out to participating groups with materials and support to help them evaluate and strengthen their fundraiser.
Accountability: Development Coordinator
Due Date: January 2015 and ongoing
Cost: Indirect staff time
- 2.3.1.2. **Action Step:** Develop and distribute an evaluation tool for participating groups to complete and return each year.
Accountability: Development Coordinator
Due Date: Annually in July
Cost: Indirect staff time
- 2.3.1.3. **Action Step:** Review and analyze each year's *OTM* campaign.
Accountability: *OTM* Planning Committee and Development Coordinator
Due Date: Annually in August, beginning in 2015
Cost: Indirect staff time
- 2.3.1.4. **Action Step:** Identify strategies to strengthen the campaign's fundraising capacity.
Accountability: *OTM* Planning Committee and Development Coordinator
Due Date: Annually in August, beginning in 2015
Cost: Indirect staff time
- 2.3.1.5. **Action Step:** Set annual *OTM* fundraising goals.
Accountability: *OTM* Planning Committee and Development Director and Staff
Due Date: Annually in October, beginning in 2015
Cost: Indirect staff time
- 2.3.2. **Objective:** Increase the number of *OTM* events.
 - 2.3.2.1. **Action Step:** Create and promulgate targeted promotional/outreach materials and strategies to encourage participation by new groups each year.
Accountability: Development Coordinator
Due Date: October through January annually in October starting in 2016
Cost: \$1,000 annually
 - 2.3.2.2. **Action Step:** Set an annual goal for the number of *OTM* events to take place the following year, and create and implement strategies for reaching the goal.
Accountability: *OTM* Planning Committee and Development Director and Staff
Due Date: September annually
Cost: Indirect staff time
 - 2.3.2.3. **Action Step:** Provide recognition for all participating *OTM* events each year (in Conference years, have a recognition/celebration at Conference).
Accountability: Development Director and Staff
Due Date: July annually

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- Cost:** \$2,000 annually
- 2.3.2.4. **Action Step:** Create strategies to highlight annually the total amount raised by the *OTM* campaign to date.
Accountability: Development Director and Staff
Due Date: July annually
Cost: Indirect staff time
- 2.3.2.5. **Action Step:** Determine the desirability and feasibility of creating a single unified *OTM* website to promote *OTM* and host all *OTM* events.
Accountability: Development Director and Staff
Due Date: November 2015
Cost: Indirect staff time
- 2.4. Goal: Strengthen Grassroots Fundraising as a fundamental component in PWSA (USA)'s long-term financial sustainability.**
- 2.4.1. **Objective:** Clarify the definition and structure of Grass Roots fundraising.
- 2.4.1.1. **Action Step:** Complete an evaluation of PWSA (USA) event-based fundraising and prepare written recommendations for future structures and strategies.
Accountability: Development Director and Staff
Due Date: January 2016
Cost: \$2,500
- 2.4.1.2. **Action Step:** Create a Policies and Procedures manual for Grassroots fundraising.
Accountability: Development Director
Due Date: March 2016
Cost: \$500
- 2.4.2. **Objective:** Implement and grow a renewed event-based fundraising strategy.
- 2.4.2.1. **Action Step:** Conduct an annual evaluation of event-based fundraising.
Accountability: Development Director and Staff
Due Date: Beginning January 2016
Cost: Indirect staff time
- 2.4.2.2. **Action Step:** Annually prepare an event-based fundraising plan for the next year.
Accountability: Development Director and Staff
Due Date: Annually in October beginning in 2015
Cost: Indirect staff time

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3. Focus Area: **Awareness**

3.1. Goal: **Increase knowledge of Prader-Willi syndrome and PWSA (USA)**

3.1.1. **Objective:** Increase the visibility and knowledge of Prader-Willi syndrome and PWSA (USA).

3.1.1.1. **Action Step:** Develop and implement an integrated awareness campaign using the web, email, social media, print, video and other appropriate marketing and communication tools (Consider: Conduct research about audience; Answer the question “What’s in it for me?”; Find the emotional hot buttons; Keep the creative focus on strategy; Keep the message simple; Align the media with the audience; and Repeat the message).

Accountability: Executive Director and Development Director and Staff

Due Date: February 2015 and ongoing

Cost: Indirect staff time

3.1.1.2. **Action Step:** Encourage and recognize awareness strategies being created and implemented by chapters, local groups and families, and develop strategies for these ideas and materials to be distributed and used by other local groups (i.e., strategies to encourage “trickle up awareness”).

Accountability: Development Coordinator

Due Date: March 2015 and on-going

Cost: Indirect staff time

3.1.2. **Objective:** Create national “Spokesperson” concept for PWSA (USA).

3.1.2.1. **Action Step:** Develop profile of “Spokesperson” and plan for utilization and candidate list along with cultivation and solicitation strategy.

Accountability: Executive Director and Development Director

Due Date: June 2015

Cost: Indirect staff time

3.1.2.2. **Action Step:** Develop and implement a public relations campaign and appropriate support materials utilizing the national “Spokesperson”.

Accountability: Executive Director and Development Director and Staff

Due Date: September 2015 and ongoing

Cost: Indirect staff time

3.1.3. **Objective:** Develop and implement a consistent brand across PWSA (USA) educational, awareness, outreach and fund development resources (the web, email, social media, print, video, other).

3.1.3.1. **Action Step:** Define the PWSA (USA) brand

Accountability: Executive Director and Development Director

Due Date: July 2015

Cost: Indirect staff time

3.1.3.2. **Action Step:** Determine how PWSA campaign themes (e.g. *OTM*, *Angel*) and annual themes (e.g. *This is My Association*) are integrated as part of a single PWSA (USA) brand.

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- Accountability:** Executive Director and Development Director
Due Date: August 2015
Cost: Indirect staff time
- 3.1.3.3. **Action Step:** Complete Implementation of brand policy across all PWSA (USA) resources.
Accountability: Executive Director and Development Director
Due Date: December 31, 2015
Cost: \$3,000 annually
- 3.1.4. **Objective:** Provide high quality PowerPoint, Video and other presentations appropriate for use by PWSA (USA) and its chapters.
- 3.1.4.1. **Action Step:** Develop high quality PowerPoint, Video and other presentations.
Accountability: Executive Director and Development Director and Staff
Due Date: February 2016
Cost: \$10,000
- 3.1.5. **Objective:** Enhance our work with Media.
- 3.1.5.1. **Action Step:** Develop and maintain a list of media contacts (those who have covered PWS or may be likely to do so).
Accountability: Development and Communications Associate
Due Date: March 2016
Cost: \$500
- 3.1.5.2. **Action Step:** Enlist and empower individuals at large to contact media and develop appropriate support materials that can be utilized.
Accountability: Development and Communications Associate
Due Date: December 2016
Cost: \$2,000
- 3.1.5.3. **Action Step:** Identify and empower/train a list of individuals who can be interviewed by media.
Accountability: Development and Communications Associate
Due Date: December 2017
Cost: \$2,000
- 3.1.5.4. **Action Step:** Define a space on the website for a media room.
Accountability: Development and Communications Associate
Due Date: December 2018
Cost: Indirect staff time
- 3.1.5.5. **Action Step:** Create a mechanism for tracking media hits.
Accountability: Development and Communications Associate
Due Date: December 2018
Cost: Indirect staff time
- 3.1.5.6. **Action Step:** Evaluate and update press kit.
Accountability: Development and Communications Associate
Due Date: December 2016
Cost: \$500

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- 3.1.5.7. **Action Step:** Review organization plans for opportunities to contact media with timely, newsworthy information.
Accountability: Executive Director and Development and Communications Associate
Due Date: December 2016
Cost: \$500
- 3.1.5.8. **Action Step:** Develop a public relations plan for crisis management.
Accountability: Executive Director and Development and Communications Associate
Due Date: August 2018
Cost: Indirect staff time
- 3.2. Goal: Develop *On The Move (OTM)* as a signature May Awareness Month campaign for PWSA (USA).**
 - 3.2.1. **Objective:** Continue shaping the campaign to maximize effectiveness in increasing awareness.
 - 3.2.1.1. **Action Step:** Create and implement tools and a strategy to measure the awareness-raising growth and impact.
Accountability: Development Coordinator
Due Date: August 2015
Cost: Indirect staff time
 - 3.2.1.2. **Action Step:** Review and analyze the OTM campaign.
Accountability: Development Director and Staff
Due Date: Annually in August
Cost: Indirect staff time
 - 3.2.1.3. **Action Step:** Create materials and plan strategies that focus not only on the PWS community but on targeted audiences and the general public (Targeted audiences to include educators, medical personnel, law enforcement, providers, etc.).
Accountability: Development Director and Staff
Due Date: March 2016
Cost: Indirect staff time
 - 3.2.1.4. **Action Step:** Set *OTM* awareness-raising goals for the next year.
Accountability: Development Director and Staff with Fund Development Committee
Due Date: Annually in October
Cost: Indirect staff time
 - 3.2.2. **Objective:** Strengthen the effectiveness of participating groups.
 - 3.2.2.1. **Action Step:** Reach out to participating groups with materials and staff support to help them evaluate and strengthen the awareness raising aspect of their event.
Accountability: Development Director and Staff
Due Date: March 2015 and ongoing
Cost: Indirect staff time

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- 3.2.2.2. **Action Step:** Provide recognition to groups for their awareness-raising efforts and effectiveness.
Accountability: Development Director and Staff
Due Date: July 2016 and annually thereafter
Cost: \$1,000 annually

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4. Focus Area: **Research**

4.1. Goal: **Increase and strengthen the sustainability of research funding for PWS**

4.1.1. **Objective:** Maintain an active research fund which will raise \$800,000 over the five term of the plan according to the following progression: Year 1 \$100,000, Year 2 \$125,000, Year 3 \$150,000, Year 4 \$200,000, and Year 5 \$225,000.

4.1.1.1. **Action Step:** Work more closely with the Fund Development Committee on research fundraising

Accountability: Director of Research and Development Director

Due Date: Beginning in April 2015 and ongoing thereafter

Cost: Indirect Staff time

4.1.1.2. **Action Step:** Promote what we do in research to the membership and public by increasing the use of social medial tools

Accountability: Director of Research, Development Coordinator, Family Support and Web Coordinator

Due Date: Ongoing

Cost: Indirect staff time

4.1.1.3. **Action Step:** Promote Federal and NIH research funding for PWS through advocacy

Accountability: Director of Research, Research Advocacy Coordinator, Research Committee, Scientific Advisory Board (SAB) and Clinical Advisory Board (CAB)

Due Date: Ongoing

Cost: Indirect staff time, possible travel \$1,000 yearly

4.1.1.4. **Action Step:** Make three foundation/organization appeals yearly

Accountability: Director of Research

Due Date: Starting January 2015 and ongoing thereafter

Cost: Indirect staff time

4.2. Goal: **Significantly increase PWS and hyperphagia research collaboration**

4.2.1. **Objective:** Hold a Scientific Conference every year (unless unforeseen circumstance prevail) to facilitate scientific discussion and dialogue, and host a 3rd and 4th hyperphagia focused conference/meeting by 2019.

4.2.1.1. **Action Step:** Review the outcome of the 2014 Obesity Week conference PWS events and the Scientific dinner and meeting

Accountability: Director of Research, Research Advocacy Chairperson, SAB, and CAB Chairpersons

Due date: February 2015

Cost: \$10,000 was committed to 2014 Obesity Week conference from PWSA (USA), and Indirect staff time – evaluate the financial outcome regarding how much outside funding was raised and estimate cost of a 2016 conference focused on hyperphagia.

4.2.1.2. **Action Step:** Evaluate the 2014 and 2015 conferences for the following three year planning

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Accountability: Conference Committee, Chairs of SAB and CAB, BOD chair, Director of Research, Research Advocacy Chairperson

Due Date: For 2016, 2017 & 2018 Scientific Conference – February 2015

Cost: Indirect staff time

4.2.2. **Objective:** Collaborate with other organizations and institutions that have a specific interest in PWS and/or hyperphagia research, and rare disorder research

4.2.2.1. **Action Step:** Continue to work with FPWR on the PWS Therapeutic Development Team

Accountability: Director of Research, PWSA (USA) Research Advocate Chairperson, Chairperson of Therapeutic Development Team

Due date: Ongoing with conference calls at a minimum of four times a year

Cost: Indirect staff time

4.2.2.2. **Action Step:** Continue the relationship, through meetings, calls and e-mails with the NIH RDCRN grant, ORDR and CPAG

Accountability: Director of Research, CAB chairperson and SAB Chairperson, and Research Advocate Chairperson

Due Date: with the RDCRN grant coming to a close, , the relationship efforts will remain, but the intensity and nature of involvement may change

Cost: Indirect staff time; travel costs have been absorbed under the NIH grant but that will be discontinued in 2015. Costs of \$750 a year should be added to the budget.

4.2.2.3. **Action Step:** Develop a stronger relationship with Pennington and other obesity research institutes within NIH through working together on the hyperphagia conferences and follow up grants

Accountability: Director of Research, Research Advocacy Chairperson, SAB Chairperson and CAB Chairperson

Due Date: Ongoing

Cost: Indirect staff time, possible travel \$1,000 per year

4.2.2.4. **Action Step:** Develop a relationship with the FDA to deepen their understanding of PWS issues, and to promote acceleration of clinical study approvals

Accountability: Director of Research, Research Advocacy Chairperson, Chairperson of Therapeutic Development Team

Due date: Ongoing

Cost: indirect staff time, possible travel \$1000 per year, some costs will be absorbed by NORD

4.2.2.5. **Action Step:** Develop relationships with pharmaceutical companies and support their access to patients in order to promote accelerate clinical trials on PWS

Accountability: Director of Research, Research Advocacy Chairperson, Chairperson of Therapeutic Development Team

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Due date: ongoing

Cost: indirect staff time; other cause will be absorbed by the pharmaceutical companies

4.3. Goal: Create an atmosphere where PWS research is actively pursued around the world

4.3.1. Objective: Increase PWS research awareness and interest

4.3.1.1. **Action Step:** Host awareness booth at medical conferences and information on the web site, thus PWSA (USA) will leverage the uniqueness of PWS (food addiction, hyperphagia, genetics/imprinting, metabolics (weight distribution, body structure), hypothalamic dysfunction) and its potential to shed light on universal illness (especially obesity and diabetes) to maximize its leverage with external organizations.

Accountability: Director of Research, Research Advocacy Chairperson, Development Coordinator, CAB Chairperson, SAB Chairperson

Due date: Two awareness booths at medical conference per year -- Ongoing

Cost: \$6,000 per year; indirect staff time; outside funding was obtained for 2014 – one event paid for by IPWSO; funding will be pursued yearly through grants and foundation donations.

4.3.1.2. **Action Step:** Utilize our access to PWS individuals and data collected from them to support valuable research projects and create interest to researchers on needed research; evaluate ongoing need of current medical database

Accountability: Database coordinator, Director of Research, CAB Chairperson, and SAB Chairperson

Due date: Ongoing

Cost: Indirect staff time

4.3.1.3. **Action Step:** Nurture our world-class Scientific and Medical Advisory Boards to promote research, and to guide PWSA (USA) scientific decision making.

Accountability: Director of Research

Due date: Ongoing

Cost: Indirect staff time

4.3.1.4. **Action Step:** Continue to collaborate with researchers and clinicians around the world, writing and sharing valuable research and medical care information

Accountability: Director of Research, Director of Medical Affairs, IPWSO Executive Director, IPWSO President

Due date: Ongoing

Cost: Indirect staff time

4.4. Goal: Maximize the impact of research funds donated to PWSA (USA)

4.4.1. Objective: Assure appropriate and effective utilization of research funding

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- 4.4.1.1. **Action Step:** Create and announce RFA's in a professional, well publicized, open, and appropriate manner
Accountability: Director of Research, PWSA (USA) Research Chairperson, SAB Chairperson
Due date: Ongoing – minimum of once a year
Cost: Indirect staff time, funds raised for research
- 4.4.1.2. **Action Step:** Include the following criteria for research for funding:
- Focus on applied research
 - Research of special interest to the PWS research committee and membership
 - Support for researchers with a long standing interest in PWS as well as less experienced investigators with strong potential to be vested in the syndrome
 - American and international research
- Accountability:** Director of Research, PWSA (USA) Research Chairperson and Committee, SAB Chairperson
Due date: Ongoing
Cost: Indirect staff time, funds raised for research
- 4.4.1.3. **Action Step:** Coordinate research funding announcements with FPWR's RFA's
Accountability: Director of Research, PWSA (USA) Research Chairperson, FPWR Research Chairperson
Due date: Initiated in 2011 – ongoing
Cost: Indirect staff time
- 4.4.1.4. **Action step:** Assure that all research projects meet the criteria of the SAB, Research Committee, and the Board of Directors
Accountability: Director of Research, PWSA (USA) Research Chairperson, and SAB Chairperson
Due date: Ongoing
Cost: Indirect staff time
- 4.4.1.5. **Action step:** Recruit medically knowledgeable parents to work on Research Committee
Accountability: Director of Research
Due date: Ongoing
Cost: indirect staff time

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5. Focus Area: **Medical Intervention and Support**

5.1. Goal: **Provide medical response system for Prader-Willi syndrome (PWS).**

5.1.1. **Objective:** Triage all urgent medical questions.

5.1.1.1. **Action Step:** Ensure that all urgent medical questions via phone and e-mail go to the Medical Affairs Coordinator and/or backup within an hour.

Accountability: Office manager and all staff triaging the phone and emails

Due Date: On-going

Cost: Indirect staff time

5.1.2. **Objective:** Respond to all urgent medical questions within the day.

5.1.2.1. **Action Step:** Evaluate the urgency and needed response.

Accountability: Director of Medical Affairs and/or backup

Due Date: On-going

Cost: Indirect staff time

5.1.3. **Objective:** Triage all non-urgent medical questions.

5.1.3.1. **Action Step:** Ensure all non-urgent medical questions via phone and e-mail go to the Medical Affairs Coordinator and/or backup within a day

Accountability: Office manager and all staff triaging the phone and e-mails.

Due Date: On-going

Cost: Indirect staff time

5.1.4. **Objective:** Respond to all non-urgent medical questions within five working days.

5.1.4.1. **Action Step:** Evaluate priorities and needed response.

Accountability: Medical Affairs Coordinator and/or backup

Due Date: On-going

Cost: Indirect staff time

5.1.5. **Objective:** Expand medical response team.

5.1.5.1. **Action Step:** Assure we do not overuse our Clinical Advisory Board (CAB) members, by contracting with psychiatric and medical experts on PWS to respond to more complex issues.

Accountability: Medical Affairs Coordinator, Executive Director, CAB members

Due Date: January 2015

Cost: \$20,000

5.2. Goal: **Educate the families, health care professionals and the public regarding PWS medical issues.**

5.2.1. **Objective:** Create and provide adequate and updated medical educational booklets, brochures and DVDs.

5.2.1.1. **Action Step:** Work with the Publication Committee and Clinical Advisory Board on materials needing revisions and creating a minimum of one new publication yearly.

Accountability: Medical Affairs Coordinator and Crisis Counselor

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- Due Date:** All medical material to be reviewed by December yearly and a minimum of one new publication by December yearly
Cost: Average of \$20,000 per year – to be covered primarily by designated funding and grants
- 5.2.1.2. **Action Step:** Hire a part time staff to help monitor, create and design medical related educational materials.
Accountability: Executive Director with input from Medical Affairs Coordinator
Due Date: January 2015
Cost: \$15,000
- 5.2.2. **Objective:** Create and provide adequate and updated medical information of the newsletter, web site and blogs.
- 5.2.2.1. **Action Step:** Decide what medical topics are pertinent to parents, care providers, and medical staff. Assure that medical articles and alerts are written by and/or reviewed by members of the CAB or SAB.
Accountability: Medical Affairs Coordinator and appropriate members of the CAB
Due Date: For the newsletter, at copy deadline; for the web site and blogs as appropriate with urgent alerts posted within three working days
Cost: Indirect staff time
- 5.2.3. **Objective:** Sponsor two medical awareness booths yearly at major medical conferences (overlaps with research goal).
- 5.2.3.1. **Action Step:** Review with CAB and SAB Chairpersons the most appropriate conferences to sponsor a booth at each year. Rotate between specialties relevant to PWS.
Accountability: Director of Medical Affairs
Due Date: Two medical booths a year chosen by February each year
Cost: \$6,000 per year; indirect staff time; outside funding has been obtained for 2015 and will be pursued yearly through grants
- 5.3. Goal: Create a better understanding of the causes of death in persons with PWS and provide bereavement support for families.**
- 5.3.1. **Objective:** Investigate causes of death.
- 5.3.1.1. **Action Step:** Evaluate if this service can be provided through a volunteer or is best provided by the role of a new paid staff (part time).
Accountability: Medical Affairs Coordinator and Management Team
Due Date: March 2015
Cost: Materials = \$700 per year; if paid staff = six hours a week
- 5.3.2. **Objective:** Provide bereavement support and booklets for parents, siblings and persons with the syndrome.

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5.3.2.1. **Action Step:** Evaluate if this service can be provided through a volunteer or is best provided by the role of a new paid staff (part time).

Accountability: Medical Affairs Coordinator and Management Team

Due Date: March 2015

Cost: Materials = \$500 per year; if paid staff = four hours a week

5.4. Goal: For PWSA (USA) to continue to be the leading international resource for medical materials.

5.4.1. **Objective:** Share medical materials internationally via email and the web.

5.4.1.1. **Action Step:** Share all pertinent medical articles created by PWSA (USA) with IPWSO to be distributed to all nations.

Accountability: Director of Medical Affairs; IPWSO President, IPWSO Executive Director

Due Date: A minimum of four times a year when articles or booklets become available

Cost: Indirect staff time; mailing and translations primarily covered by IPWSO or international IPWSO member countries

5.4.2. **Objective:** Provide Spanish translations of medical materials and allow translations in all languages.

5.4.2.1. **Action Step:** Solicit Spanish speaking members to translate materials and send to IPWSO Executive Director to send to 90+ member countries with the encouragement to have professionals from their country translate if desired.

Accountability: Medical Affairs Coordinator; IPWSO President, IPWSO Executive Director

Due Date: On-going

Cost: Indirect staff time

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6. Focus Area: **Education**

6.1. Goal: Strive to be a world leader in which the development of and instruction in the knowledge of PWS is accessible and timely to families, educators, medical and law enforcement personnel, residential providers, and the community at large.

6.1.1. Objective: Support new and established residential providers.

6.1.1.1. **Action Step:** Acknowledge and support new and established residential providers by inclusion in the provider and general membership database and grants them all of the privileges associated with PWSA membership.

Accountability: PWSA (USA) Staff and Volunteers

Due Date: On-going

Cost: Relevant portion of database costs

6.1.1.2. **Action Step:** Support new and established residential providers through in-person and electronic sharing of ideas, access to and review of publications, and on-site training and consultation, as approved by the Crisis Team Leader or his/her designee.

Accountability: PWSA (USA) Staff and Volunteers

Due Date: On-going

Cost: Not to exceed approved and available crisis funds

6.1.1.3. **Action Step:** Support new and established residential providers by reviewing current and producing new publications to address specific issues faced by residential providers.

Accountability: PWSA (USA) Staff, Publications Committee and Volunteers

Due Date: On-going

Cost: Up to \$5000 annually

6.1.1.4. **Action Step:** Support new and established residential providers by planning and implementing a Provider-specific conference every year.

Accountability: PWSA Staff, Conference Committee, Professional Provider's Advisory Board

Due Date: Each year by date planned

Cost: Budget neutral conference revenue/expense

6.1.2. Objective: Develop and provide educational materials for families.

6.1.2.1. **Action Step:** Send out Package of Hope to families with new diagnosis. This packet will contain material appropriate to new families. The material will be reviewed and updated periodically.

Accountability: Crisis Team and Publications Committee

Due Date: Ongoing

Cost: Printing and publication fees not to exceed \$2000 annually

6.1.2.2. **Action Step:** Connect new families with trained mentors who will contribute to the education of PWS to the families. Mentors will be

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- trained by previously successful mentors and the Crisis Team staff and will be provided with appropriate information.
Accountability: Crisis Team
Due Date: On-going
Cost: Indirect staff time
- 6.1.2.3. **Action Step:** Develop webinars of topics of interest to address the needs of families.
Accountability: Conference Committee
Due Date: Two webinars in each non-conference year
Cost: Under \$500
- 6.1.2.4. **Action Step:** Explore the creation of sample behavior strategies for in home use to share with families.
Accountability: Crisis Team
Due Date: December 2015
Cost: Indirect staff time
- 6.1.2.5. **Action Step:** Explore the creation of a DVD directed to families to provide education about home-based behavioral interventions.
Accountability: Crisis Team, Publications Committee
Due Date: December 2015
Cost: Unknown—will be discovered in exploratory process
- 6.1.3. **Objective:** Develop and provide educational and support material for PWS for Educators.
- 6.1.3.1. **Action Step:** Send out Educator Packet to educators when requested.
Accountability: Crisis Team and Publications Committee
Due Date: On-going
Cost: Printing and publication fees not to exceed \$2000 annually
- 6.1.3.2. **Action Step:** Explore the concept of developing a regional program to train educational mentors.
Accountability: Crisis Team
Due Date: June 30, 2016
Cost: Potential travel and electronic support costs, staff time as approved by the current budget year structure
- 6.1.4. **Objective:** Develop and provide instructional materials to medical personnel.
- 6.1.4.1. **Action Step:** Provide literature as requested by medical personnel.
Accountability: Crisis Team, Office staff and Publications Committee
Due Date: On-going
Cost: Printing and publication fees not to exceed \$2000 annually
- 6.1.4.2. **Action Step:** Produce new and update current publications designed to educate medical personnel.
Accountability: Publications Committee with Director of Research, Director of Medical Affairs, Crisis Team, Family Support Committee, CAB, SAB
Due Date: Ongoing

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- Cost:** Printing and publication fees not to exceed \$2000 annually
- 6.1.4.3. **Action Step:** Continue to operate and maintain a website which will educate medical personnel and provide current and accurate information about PWS.
Accountability: Webmaster, Publications Committee, Director Medical Affairs
Due Date: Ongoing
Cost: Related web management costs
- 6.1.4.4. **Action Step:** Continue to hold a scientific conference.
Accountability: Conference Committee, SAB, CAB, Director of Research and Director of Medical Affairs
Due Date: Annually, or as determined by those accountable
Cost: Budget neutral conference revenue/expense
- 6.1.4.5. **Action Step:** Provide PWSA (USA) staff for at least 2-3 booths per year at select national medical conferences.
Accountability: Director of Medical Affairs
Due Date: Annually
Cost: Related booth registration and staff travel expenses, not to exceed \$5000 annually
- 6.1.4.6. **Action Step:** Explore two new options per year to promote the Scientific Conference so as to increase researcher and physician attendance.
Accountability: Conference Committee, SAB, CAB, Director of Research, Director of Medical Affairs
Due Date: Annually, or as determined by those accountable
Cost: Indirect staff time
- 6.1.4.7. **Action Step:** Develop a plan to educate medical personnel about PWS by seeking input from PWSA members in the medical field.
Accountability: Publications Committee, Crisis Team, Director of Medical Affairs
Due Date: January 2016
Cost: Indirect staff time
- 6.1.5. **Objective:** Develop and provide instructional materials to law enforcement personnel.
- 6.1.5.1. **Action Step:** Respond to questions and concerns by law enforcement and court personnel as the need arise, providing necessary written materials.
Accountability: Crisis Team, Office Staff
Due Date: On-going
Cost: Indirect staff time
- 6.1.5.2. **Action Step:** Develop materials and identify methods to train law enforcement personnel, seeking input from PWSA members in the law enforcement field.

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Accountability: Publications Committee, Crisis Team, Family Support Committee

Due Date: December 2015

Cost: Printing and graphics fees, not to exceed \$2000 annually

- 6.1.5.3. **Action Step:** Produce new and update current publications designed to educate law enforcement personnel.

Accountability: Publications Committee, Crisis Team

Due Date: April 2016 and on-going

Cost: Printing and graphics fees, not to exceed \$2000 annually

- 6.1.5.4. **Action Step:** Explore the possibility of establishing a court/law enforcement liaison position (volunteer) to assist with the implementation and oversight of this objective.

Accountability: Family Support Committee, Crisis Team, Office staff

Due Date: January 2017

Cost: Indirect staff time

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7. Focus Area: New Diagnoses Support

7.1. Goal: Provide mentoring to parents of newly diagnosed persons with Prader-Willi syndrome.

7.1.1. **Objective:** Ensure that PWSA (USA) will be the primary resource for families of newly diagnosed persons with PWS requiring support, education and advocacy assistance.

7.1.1.1. **Action Step:** Create, supervise and/or moderate online social media (and other) venues by facilitating communication and a sense of community between newly diagnosed parents, parent mentors and PWSA (USA) Parent Mentoring Program staff.

Accountability: New Parent Support Coordinator and New Parent Support Specialist

Due Date: December 2016

Cost: Staff time

7.1.1.2. **Action Step:** Provide parents lines of communication with experts in Prader-Willi syndrome by creating a series of Webinars with Dr. Jennifer Miller (and others) for new parents.

Accountability: New Parent Support Coordinator and New Parent Support Specialist

Due Date: Ongoing

Cost: Staff time

7.1.1.3. **Action Step:** Continue to educate and advocate on behalf of PWSA (USA) through social media, annual conferences and PWSA (USA) website and continue to support and provide up to date materials on PWS.

Accountability: New Parent Support Coordinator and New Parent Support Specialist

Due Date: Ongoing

Cost: Staff time

7.1.2. **Objective:** Enhance the Parent Mentor Support Program

7.1.2.1. **Action Step:** Increase the overall number of qualified parent mentors to a level capable of providing support to an increasing number of newly diagnosed persons with PWS.

Accountability: New Parent Support Coordinator and New Parent Support Specialist

Due Date: September 2019

Cost: Staff time

7.1.2.2. **Action Step:** Identify new mentors in states where mentors are not currently available.

Accountability: New Parent Support Coordinator and New Parent Support Specialist

Due Date: September 2019

Cost: Staff time

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- 7.1.2.3. **Action Step:** Provide additional training and support for new parent mentors.
Accountability: New Parent Support Coordinator and New Parent Support Specialist
Due Date: September 2019
Cost: Staff time
- 7.1.2.4. **Action Step:** Collaboration with Parent Mentor volunteers and PWSA (USA) Family Support Staff to implement strategies to best support families with a new diagnosis of PWS by conducting the Webinar series for Parent Mentors.
Accountability: New Parent Support Coordinator and New Parent Support Specialist
Due Date: Ongoing
Cost: Staff time
- 7.1.2.5. **Action Step:** Identify education and training for the staff of the New Parent Mentoring Program by establishing appropriate continuing educations programs, conferences and or workshops that will enhance the Parent Mentoring Program.
Accountability: New Parent Support Coordinator and New Parent Support Specialist
Due Date: September 2016
Cost: Staff time
- 7.1.2.6. **Action Step:** Extend the Mentoring Program to Grandparents by creating a social media online venue for Grandparents to learn more about PWS and receive support from other Grandparents.
Accountability: New Parent Support Coordinator and New Parent Support Specialist
Due Date: June 2016
Cost: Staff time
- 7.1.2.7. **Action Step:** Conduct a Workshop/Retreat for mothers' that have recently received the diagnosis of PWS by coordinating and facilitating a "Mother's Retreat of Respite and Empowerment" - a weekend of relaxation for mom's and an opportunity to meet and connect with their assigned Parent Mentors.
Accountability: New Parent Support Coordinator and New Parent Support Specialist
Due Date: June 2017
Cost: Staff time and other cost to be determined for 2017 Budget
- 7.1.3. **Objective:** Increase the number of new diagnoses know to PWSA (USA).
 - 7.1.3.1. **Action Step:** For 2016, increase to 200 new diagnoses by identifying families through social media, continuing to monitor PWS (USA) website for completed New Diagnosed Forms and monitoring Google

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searches to ensure that PWSA (USA) is the first organization that appears in a search.

Accountability: New Parent Coordinator and New Parent Support Specialist

Due Date: December 2016

Cost: Staff time

- 7.1.3.2. **Action Step:** Increase the total number of new diagnoses to pre-FPWR levels. Note: the average yearly number of new diagnoses has declined over the time period since FPWR was founded.

Accountability: New Parent Coordinator and New Parent Support Specialist

Due Date: September 2016

Cost: Staff time

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8. Focus Area: **Advocacy**

8.1. Goal: **Provide support for the PWSA (USA) ideas and/or causes**

8.1.1. **Objective:** Establish a committee at the national level to set criteria and goals for advocacy.

8.1.1.1. **Action Step:** Ensure committee consists of a chairperson, one staff member and other appointed individuals with expertise and / or interest in advocacy for individuals with PWS.

Accountability: Executive Committee

Due date: January 31, 2016

Cost: Volunteer and indirect staff time

8.1.1.2. **Action Step:** Establish advocacy information on PWSA (USA) family support and crisis needs.

Accountability: Advocacy Committee

Due date: **May 31, 2017**

Cost: Volunteer and indirect staff time

8.1.1.3. **Action Step:** Research and analyze legislative issues which impede service access.

Accountability: Advocacy Committee

Due date: **May 31, 2017**

Cost: Volunteer and indirect staff time

8.1.1.4. **Action Step:** Research and analyze national disability laws which protect individuals and their families.

Accountability: Advocacy Committee, Chapter Relations Committee

Due date: October 31, 2017

Cost: Volunteer and indirect staff time

8.1.1.5. **Action Step:** Have an advocacy committee member **and** appointed person attend the **ARC Disability Policy Seminar in Washington. D.C.**

Accountability: Advocacy Committee Member **and** appointed person

Due date: **March 20-22, 2017 and annually thereafter.**

Cost: **\$2,500** each participating year

8.1.16. **Action Step:** Have an advocacy committee member or appointed person attend a NORD regional meeting.

Accountability: **Advocacy Committee**

Due Date: **March 2017 and annually thereafter**

Cost: **\$1,000** each participating year

8.1.2. **Objective:** Have a disabilities Advocacy Specialist at the national office.

8.1.2.1. **Action Step:** Employ a disabilities advocacy specialist whose specific task would be to coordinate legislative advocacy issues and concerns at the national office

Accountability: Executive Director, Advocacy Committee

Due date: January 31, 2019

Cost: \$45,000.00 annually

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- 8.1.3. **Objective:** Establish a team (Advocacy State Team) consisting of a representative from each PWSA (USA) existing state chapter to set criteria and goals for advocacy in their individual states.
- 8.1.3.1. **Action Step:** Ensure team consists of a team leader, one staff member (Advocacy Specialist) and other appointed individuals from each Chapter with expertise and / or interest in advocacy for individuals with PWS.
Accountability: Executive Director, Advocacy Committee, Chapter Relations Committee
Due date: August 31, 2017
Cost: Volunteer time, staff time, \$100 to set up web action groups
- 8.1.3.2. **Action Step:** Research and analyze state developmental disability service eligibility and system support processes and funding streams.
Accountability: Advocacy Committee, Advocacy State Team
Due date: October 31, 2017
Cost: Volunteer time, indirect staff time
- 8.1.3.3. **Action Step:** Research, analyze and identify state, local offered advocacy systems.
Accountability: Advocacy Committee, Advocacy State Team
Due date: October 31, 2017
Cost: Volunteer time, indirect staff time
- 8.1.3.4. **Action Step:** Research by state qualified, disability lawyers and develop working relationships for chapter needs.
Accountability: Advocacy Committee, Advocacy State Team
Due date: October 31, 2017
Cost: Volunteer time / staff support
- 8.1.3.5. **Action Step:** Compile finding from action step 8.1.3.2 – 8.1.3.4 and create an informational online Advocacy Support Guide for navigating state service systems.
Accountability: Advocacy Committee, Advocacy Specialist
Due date: July 31, 2018
Cost: Volunteer time, indirect staff time, \$100 for online programming
- 8.1.3.6. **Action Step:** Review online Advocacy Support Guide with Chapter Leaders annually via conference or telephonic meeting.
Accountability: Advocacy Committee, Chapter Leaders, Advocacy State Team
Due date: Annually after following July 2018 compilation of online Advocacy Support Guide
Cost: Volunteer time, \$100 for online updates
- 8.1.4. **Objective:** Ensure Prader-Willi syndrome is listed as a development disability on Federal and State levels.
- 8.1.4.1. **Action Step:** Go through the process to make this happen on a federal level.

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Accountability: Advocacy Committee

Due date: December 31, 2018

Cost: Volunteer time

- 8.1.4.2. **Action Step:** Determine which states will accept federally listed developmental disabilities as automatically state qualified.

Accountability: Advocacy Committee, Advocacy State Team

Due date: June 30, 2019

Cost: Volunteer time

- 8.1.4.3. **Action Step:** Ensure Prader-Willi syndrome is listed as a developmental disability on state levels that do not accept federal level qualification of disabilities.

Accountability: Advocacy Committee, Advocacy State Team

Due date: July 31, 2019

Cost: Volunteer time

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9. Focus Area: Chapters, Affiliates, and Local Support

9.1. Goal: Develop, strengthen and nurture state chapters and affiliates.

9.1.1. **Objective:** Established a PWSA Chapter or Chapter Affiliate in each state in the United States.

9.1.1.1. **Action Step:** Identify needs of states without a support chapter.

Accountability: Chapter Relations Committee

Due date: March 31 of each year. Ongoing.

Cost: Volunteer time, indirect staff time

9.1.1.2. **Action Step:** Identify a key person in states without a support chapter to encourage and support in the creation of a state chapter.

Accountability: Chapter Relations Committee

Due date: March 31 of each year. Ongoing.

Cost: Volunteer time / indirect staff time

9.1.1.3. **Action Step:** Support new chapters in the dissemination of information pertaining to advocacy and support for families with children with PWS.

Accountability: Chapter Relations Committee, Advocacy Committee

Due date: 2015 and on-going

Cost: Volunteer time, indirect staff time

9.1.2. **Objective:** Ensure each person in the U.S.A. who is affected by PWS has a strong and viable state chapter or chapter affiliate of PWSA (USA). The chapters and PWSA (USA) effectively divide responsibilities.

9.1.2.1. **Action Step:** Establish written step by step best practices (checklist) that each state can aspire to achieve in order to build a strong state organization.

Accountability: Board Chairperson, Chapter Relations Committee

Due Date: March 31, 2016

Cost: Indirect staff time

9.1.2.2. **Action Step:** Contact each state and assess where the state is on the best practices checklist.

Accountability: Staff, Board Chairperson, Chapter Relations Committee

Due Date: June 30, 2016

Cost: Volunteer and staff time

9.1.2.3. **Action Step:** Set up specific supports that correspond with each action step and implement support to help state achieve next level in checklist.

Accountability: Staff, Chapter Relations Committee

Due Date: March 31, 2016

Cost: Indirect staff time

9.1.2.4. **Action Step:** Help each state move up at least one step in the checklist every year.

Accountability: Board Chairperson, Staff, Volunteers, Chapter Relations Committee

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- Due Date:** 2016 and ongoing
Cost: Indirect staff time
- 9.1.2.5. **Action Step:** Hold an annual PWSA (USA) meeting with chapter leaders.
Accountability: Board Chairperson, Conference Committee, Chapter Relations Committee
Due Date: Annually
Cost: \$3200 and indirect staff time
- 9.1.2.6. **Action Step:** Ensure PWSA (USA) and its Chapters and Chapter Affiliates engage in an ongoing dialog to identify and address matters that are best addressed locally and/or with a combination of national and local resources (e.g.: mentoring, creating and identifying residential facilities; promoting and identifying vocational opportunities; identifying medical specialists; advocacy with respect to matters of state law; networking; educational issues).
Accountability: Board Chairperson, Chapter Relations Committee, Advocacy Committee
Due Date: On-going
Cost: Indirect staff time
- 9.1.2.7. **Action Step:** PWSA (USA) will provide meaningful content and discussion at regular intervals on CLE email group.
Accountability: Chapter Relations Committee, Staff
Due Date: On-going
Cost: Indirect staff time
- 9.1.2.8. **Action Step:** Work with PWSA (USA) and its Chapters and Chapter Affiliates, to create and maintain on its website a resource area including templates or resources in such areas as fundraising, legislative advocacy, college and day programs, residential facilities, vocational opportunities, and possible chapter conferences for parents and clinicians
Accountability: Board Chairperson, Chapter Relations Committee
Due Date: December 2015 and ongoing
Cost: Indirect staff time
- 9.2. Goal: Encourage chapters and affiliates to support PWSA (USA)**
- 9.2.1. **Objective:** Ensure that State Chapters and Affiliates view themselves as part of PWSA (USA) to the extent that they enthusiastically support PWSA (USA) by encouraging state members to renew memberships annually, by conducting fundraisers for PWSA (USA), and by volunteering to accomplish objectives of PWSA (USA).
- 9.2.1.1. **Action Step:** Identify 2-3 methods and incentives for attracting members to renew annual membership.
Accountability: Chapter Relations Committee
Due Date: March 31, 2016 and ongoing

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- Cost:** Indirect staff time
- 9.2.1.2. **Action Step:** Visit or contact each state and offer the incentives and encourage participation.
Accountability: Executive Director, Chapter Relations Committee
Due Date: Quarterly Contact.
Cost: Indirect staff time and \$3,500 for travel
- 9.2.1.3. **Action Step:** Encourage each state to conduct an *On The Move* Awareness and Fundraising event each year by contacting the state and encouraging participation and assistance.
Accountability: Chapter Relations Committee
Due Date: February-April each year starting in 2015. Ongoing.
Cost: Indirect staff time

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10. Focus Area: National Conferences

10.1. Goal: Provide forums on biennial basis for PWS families and/or professionals to collaborate through the exchange of information and education.

10.1.1. **Objective:** Ensure oversight and accountability through all aspects of pre-conference planning, budgets, and implementation of event.

10.1.1.1. **Action Step:** Appoint, develop and support a representative who will maintain the leadership role as conference chairperson.

Accountability: PWSA (USA) Board Chairperson, Executive Director

Due Date: Two years prior to conference date, ongoing through post conference review

Cost: No cost, volunteer position, unless otherwise identified in the approved conference budget

10.1.1.2. **Action Step:** Appoint, develop and support a committee of individuals responsible for identified tasks within the conference structure.

Accountability: Conference Committee Chairpersons

Due Date: Two years prior to conference date, ongoing through post conference review

Cost: No cost, committee members should be volunteer positions, unless otherwise identified in the approved conference budget

10.1.1.3. **Action Step:** Ensure conference structure supports key areas of interest to the PWS Community by appointing sub-committee chairs (i.e. Scientific, Professional Providers, General, Volunteers and Youth and Adult Programs).

Accountability: PWSA (USA) Board Chairperson, Executive Director, Conference Committee Chairpersons

Due Date: One year prior to conference date, ongoing through post conference review

Cost: No cost, volunteer positions, unless otherwise identified in the approved conference budget

10.1.1.4. **Action Step:** Ensure opportunities for networking and enhancing the PWS Community through structured social gatherings, i.e. Welcome receptions, General Gala, YAP Gala.

Accountability: PWSA (USA) Executive Director, Conference Committee Chairpersons, Sub- committee chairs

Due Date: One year prior to conference date, ongoing through post conference review

Cost: No cost, volunteer positions, unless otherwise identified in the approved conference budget

10.1.2. **Objective:** Identified a physical location to hold conference.

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- 10.1.2.1. **Action Step:** Site visits should be conducted at identified conference location to ensure the date availability, structural layout, room capacity, amenities, budget criteria and flexibility to meet PWS environmental supports.
Accountability: Conference Committee Chairpersons, identified committee members, PWSA (USA) Executive Director and Office Manager, and conference planner if one is identified.
Due Date: Two years prior to conference date
Cost: Need to be reflected within the conference proposed budget
- 10.1.2.2. **Action Step:** Work with hotel events manager to develop a contract that meets the needs and budgetary requirements.
Accountability: Conference Committee Chairpersons, PWSA (USA) Executive Director, and Office Manager, and conference planner if one is identified.
Due Date: Two years prior to conference date
Cost: \$10,000 deposit. Needs to be reflected within the conference proposed budget
- 10.2. Goal: To be fiscally solvent post conference.**
 - 10.2.1. **Objective:** Use fund raising and marketing strategies for each conference.
 - 10.2.1.1. **Action Step:** Create and submit a proposed budget that reflects both income and all known expenses.
Accountability: Conference Committee Chairpersons. Reviewed and approved by the Board of Directors one year prior to conference dates.
Due Date: Based on proposed conference dates
Cost: \$325,000 - \$400,000
 - 10.2.1.2. **Action Step:** Facilitate active support through sponsorship, grants, private donations, and fund raising efforts.
Accountability: Conference Committee Chairpersons, PWSA (USA) Board Chairperson, Executive Director, and Fund Development Committee Chairperson.
Due Date: One year prior to conference
Cost: Volunteer position and paid staff salaries
 - 10.2.1.3. **Action Step:** Distribute line item budgets to each sub-committee chair, outlining funds available for their specific program area of conference program.
Accountability: Conference Committee Chairpersons
Due Date: Eight months prior to event
Cost: As outlined in approved budget
 - 10.2.1.4. **Action Step:** Post conference review of all income and expenses to be submitted to the Board of Directors.

Strategic Plan (2015-19)

Accountability: Conference Committee Chairpersons, PWSA (USA)
Executive Director and Office Manager.

Due Date: January Board Meeting

Cost: Volunteer position and paid staff salaries

Strategic Plan (2015-19)

11. Focus Area: **External Collaborative Relationships**

11.1. Goal: **Work collaboratively with external stakeholders.**

11.1.1. **Objective:** Explore, create or maintain / advance working relationships with the following organizations: Foundation for Prader-Willi Research; National Organization of Rare Diseases; Genetic Alliance; Rare Disease Clinical Research Network; Genetic Disease Foundation; NIH Office of Rare Diseases; Pennington Research Center; International Prader-Willi Syndrome Organization; Coalition of Patient Advocacy; American Association of People with Disabilities; Association for People with Intellectual Disabilities; Residential Service Organizations (TBD) and others.

11.1.1.1. **Action Step:** Create written collaborative objectives for each of these organizations.

Accountability: Staff

Due Date: July 31, 2015

Cost: Indirect staff time

11.1.1.2. **Action Step:** Develop written criteria for collaborative relationships with outside organizations to insure that they support PWSA USA mission and objectives for Research, Support, Advocacy, Fundraising, Efficient Operation, and Cost Savings.

Accountability: Executive Director, Board Chairperson

Due Date: September 30, 2015

Cost: Indirect staff time

11.1.1.3. **Action Step:** Create written objectives and explore / identify potential collaborative partners in the areas of Residential Settings (i.e. REM, PWHO, etc.) and Crisis Services (TCI, etc.).

Accountability: Executive Director and staff

Due Date: June 1, 2016

Cost: Indirect staff time, possible travel \$5,000 in 2015 and 2016

Note:

Board and staff were polled to create list in Objective 11.1.1 with total budget (+/_) of \$10,000 with \$5,000 in 2015 and \$5,000 in 2016.

Strategic Plan (2015-19)

12. Focus Area: **Administration**

12.1. Goal: Provide effective management of the PWSA (USA) by developing a well-balanced, team oriented, well trained workforce that is diverse, agile, committed to the organization's mission, and continuously expanding their capabilities to shape the organization's future.

12.1.1. **Objective:** Encourage professional development and commit to hiring more experienced staff.

12.1.1.1. **Action Step:** Complete performance development plans for all staff that build on the department goals which are built on the strategic plan of the organization.

Accountability: All staff who manage other staff

Due Date: Dec 31, 2015 and ongoing

Cost: Indirect staff time

12.1.2. **Objective:** Enhance employee satisfaction through team development.

12.1.2.1. **Action Step:** Develop an employee recognition program.

Accountability: Executive Director

Due Date: June 30, 2016

Cost: Unknown at this time

12.2. Goal: Improve the understanding of the organization's financial matters by management, the Finance Committee, and the Board of Directors.

12.2.1. **Objective:** Provide financial information and interpretations to the Finance Committee Chairperson and PWSA (USA) management within two weeks after the close of a business month.

12.2.1.1. **Action Step:** Maintain up to date and accurate records to ensure timely reporting.

Accountability: Executive Director and Accounting staff

Due Date: March 31, 2015

Cost: Indirect staff time

12.2.2. **Objective:** Accurately account for income and expenses in a way that allows for ease of reporting, reconciliation of income and expenses associated with grants and other restricted funds, and the association of the correct organizational cost center (department).

12.2.2.1. **Action Step:** Develop a chart of accounts that accurately reflects the reporting needs of the organization.

Accountability: Executive Director, Finance Chairperson, Accounting staff

Due Date: June 30, 2015

Cost: \$1000

12.3. Goal: Build effective, efficient, strategically aligned business processes that integrate and capitalize on the organization's human capital and technology resources.

12.3.1. **Objective:** Evaluate all business processes.

Strategic Plan (2015-19)

- 12.3.1.1. **Action Step:** Create streamlined processes that are in writing and shared with all staff.
Accountability: Executive Director with support from all staff
Due Date: November 30, 2015
Cost: Indirect staff time
- 12.3.2. **Objective:** Utilize technology at its greatest capacity.
 - 12.3.2.1. **Action Step:** Finance Department and Communications staff will each complete DonorPerfect training specific to their responsibilities and needs.
Accountability: Financial Development and Communications staff
Due Date: August 31, 2015
Cost: \$300 and indirect staff time
- 12.4. **Goal: All internal communications (between the Board of Directors, Executive Board, and the staff) will adhere to the highest ethical and professional standards, as well as any applicable industry-specific standards, and should exhibit transparency, fairness and honesty.**
 - 12.4.1. **Objective:** Encourage internal communication that welcomes alternative perspectives and encourages participation at all levels in order to build and maintain camaraderie. Management should actively, listen carefully and respond respectfully to the views of internal constituents.
 - 12.4.1.1. **Action Step:** Have a policy where 365 degree feedback is utilized, continue bi-weekly staff meetings, and respond to all questions and concerns.
Accountability: All staff
Due Date: On-going
Cost: Indirect staff time
 - 12.4.2. **Objective:** Board Executive Committee conference calls will be strategic calls that are aligned with policy and with the intent to inform the Executive Committee and enhance their understanding of operational issues affecting the association.
 - 12.4.2.1. **Action Step:** Conduct conference calls as needed by the Executive Director to provide a brief overview of operations and surface any concerns where support is needed.
Accountability: Executive Committee, Executive Director
Due Date: On-going
Cost: Indirect staff time