

October 2016 Board meeting summary

Investment Report: The WSA investment account realized a gain of 4.98 % this year, and 5.38% since inception in 2002.

Executive Director Report:

Expenses are expected to be 75% of projected levels. Walks were down in numbers but fundraising was up from 2015. Action will be taken in 2017 to make volunteer administration of an event easier for them with more support from WSA.

Camps were well attended, and an increase to cover rising costs (largely due to transportation) was approved. Partnership with Camp Blue Skies finalized.

Request for scholarships is growing. WSA designated \$112,000 for scholarships and \$25,000 for medical assistance in 2016. To date (9/30) \$114,000 was awarded in scholarships and \$12,000+ in travel and lodging assistance for medical treatment. We have helped 100 families to date in 2016.

WSA initiatives (AT, housing and education) have progressed per plan throughout 2016, though the pre-school AT initiative was not able to recruit the requisite 14 families to ensure a published paper, and will proceed without.

Terry spent two days on Capitol Hill in May, focusing on recognition by the Rare Disease Caucus.

Board election and by-law updates:

Members discussed merits of a 2-year vs. 3- year limit for the office of President. Board members were in agreement that there was no down-side to allowing an extra year as Board President, but that it would be considered an “exception” and utilized in special circumstances. A motion was then made and unanimously passed.

That change in by-laws was in addition to the following approved updates:

- By-laws require a biannual membership meeting – the meeting will take place at the convention.
- Board members may not receive grant funding while on the Board, or sell any WS products (t-shirts etc.)
- There is a maximum 2 year term limit for consecutive terms. However a former member may be placed on the ballot for additional terms after 1 year off the Board
- Board members must be residents of the US (not in By-laws, but understood)
- Meeting notices and by-laws must be placed on the website
- Exec Director can be removed by board
- Board meeting summary will be placed on website

Committee Updates:

Exec. Committee had established three goals for 2016 – Major By-laws revisions establishing the foundation for a succession plan for the Exec. Dir. position and updating the Board manual. By-laws revisions are complete, and the succession planning process is underway. Board manual revisions will be undertaken in the first quarter of 2017.

Research Committee: Terry discussed the WS Registry, and our need to find better ways to encourage folks to participate, make it easier to enroll and market it better. Board members noted that the process for sending in consent to get medical records is tedious because it cannot be done online.

PR/Marketing: Leading up to the White Night event for research, we will concentrate on the message that Williams syndrome is poised to be one small condition that can help millions of people worldwide. Laurel noted that she and Terry will focus on developing new positioning and strategy after the event and by the end of 2017. Laurel provided an update on White Night – they are hoping to finalize a majority of sponsor prospects by the first week in January.

There was also discussion about education, the web site and better ways to help families understand the best steps to take in setting up an education plan.

Member Support Committee:

There was discussion about the young family workgroup that was created, and the ideas that had been discussed during their phone call. The next step will be to prioritize the ideas and assign folks to aid the office staff on specific items such as leveraging social media, providing WS education to specialists, and securing vendor tables at medical meetings.

WS Adult family workgroup progress was slowed by convention, camp and Adventure Seeker reunion, as most of the work group members (and in particular Robin Pegg) were too busy to participate regularly. The initial phone call in the spring did serve to pose the questions that needed to be answered in regard to an annual calendar, “tiered” support levels at events, and registration needs. The group will be meeting again soon to discuss the details of a plan for events over the next 18 months.

Nominating Committee:

Convention was a successful networking opportunity for garnering interest in board participation. More than 8 candidates were submitted for possible inclusion on the ballot. It was noted that several were young parents (very new to the WSA) will be great in the future and can provide “task-specific” help on committees in the interim. Following the interview process, the nominating committee met by teleconference to discuss each candidate and current needs on the Board. The committee then presented the following slate for Board consideration:

Kate Bierfeldt: Candidate with Williams syndrome.

Sarah Giddings: Mother of teenage son with WS from Phoenix, AZ. Business expertise in training and development; RC for WSA for 6+ years.

Marella Holmes: Mother of teenage daughter in New Jersey. Expertise in social work and ministry as well as community outreach.

Motion: to accept the slate of nominees for the 2017-2019 was seconded and unanimously approved.

2017 Committees: Board was asked to re-commit to a committee or committees for 2017.

Executive Committee: no change: Áine, Melissa, Carol and Jeff

Finance Committee: no change Jeff, Dean, Michelle

Member Support: no change Melissa & Carol, Jocelyn, Michelle, Seth

Nominating Committee: Ron, Dean, Jeff, Jocelyn (non-Board member to be identified)

Research Committee: Jocelyn, Marty, Áine, Tricia, Rosa Cortes

Marketing Workgroup: Laurel, Terry, Dean Board

Manual Workgroup: Áine, Melissa, Tricia & Ron.

Áine reminded everyone that the Board member self-evaluation should be taken later this year before the start of 2017.

Regional Committee:

Motion to set up a formal structure for Board members to call and “Check in” with RCs was revisited. Terry will review the list and provide each Board member with 3-4 names to call (according to demographics/similar aged children etc.)

Expectations, support and best practices for volunteers: Suggestions were made around placing expectations within a framework – i.e. WSA will do “X” for you and we would like you to provide “Y”, stressing that we are “partners”. Terry and Laura will follow up with this strategy and put it into place at the February workshop.

In 2017 a high priority will be given to helping RCs develop committees to help them reach more families.

Strategic Plan – Review & Update:

Education:

An IEP tip sheet was created for parents, an educational profile was created for teachers and therapists and the Assistive Tech. program was brought to pre-school and high-school aged students. Data collection for housing and employment options is ongoing.

Medical and Research:

With the help of WS professional advisors, Terry created and distributed an RFP for an anxiety study aimed at defining problems and possible/probable treatments for anxiety in adults with WS. Ongoing partnership and work with the Lurie Center.

Community:

A full-time employee has joined the WSA staff to improve internal (national office) support to RCs and help brainstorm and initiate ways for RCs to provide better support to families. A Board-centered, young families task force was created to better understand support needs and ways to provide it.

Organization:

Several new administrative improvements were added to our convention processes and an additional staff member was added to help with event administration. As a result, awareness month was smoother, the convention was highly successful and the WSA staff is better than ever.

Goals for 2017:

- Nationwide Advocacy support program to provide both intervention and coaching services to families with school-age children
 - “Parent friendly” reviews of all current research findings on educational outcomes for students with WS to be published on website and reviewed in eNewsletter etc. Priority subjects include reading, writing, math, speech/pragmatics, AT, OT, Behavior/anxiety strategies
 - Survey parents regarding critical areas of concern and school districts requirements for published studies in order to add critical service to encourage research/prepare and distribute RFPs per funding availability
 - 15 minute (maximum) videos on website to provide training/in service to teachers—WSA will solicit videos for review (describing general content and structure (Script plus storyboard
 - Publish information regarding “best practices” in teaching for students with WS to ensure alignment to current educational/instructional theory. Grade level curriculum access will be a high priority
 - Succession planning to begin process of locating new “WS experts” in key educational areas Research & WS Registry
 - New marketing program for the WS Registry
 - Parent-friendly reports of new findings published on website
 - Partner with Clinic leadership to define “best practices” for WS treatments
 - Petition for WS specific ICD-10 code
 - Secure funding for major cardio-vascular/anesthesia studies Community
 - Distribute “discipline-specific” materials to professionals
 - Improved social media outreach and updated branding
 - Improve awareness and membership in underserved communities
 - Continued growth improvement of RC programs Organization –
 - Increase membership to 7,500
 - Upgrade database and event software
 - Maintain fundraising percentage less than 20%
 - Diversify funding resources & secure long term corp. sponsors