

Williams Syndrome Association  
Board of Trustees Meeting  
April 8, 2018

Board members present: Melissa Murphy, Tricia Purdy, Carol Patinkin, Cyndra Cole, Stella Beard, Matt Bartow, Scott Ottenheimer, Jocelyn Krebs, Laurel Rossi, Sarah Giddings, Marella Holmes, Marty Levinson, Kate Bierfeldt, Alex Streit. Absent: Jeff Baer  
Staff present: Terry Monkaba

Melissa Murphy called the meeting called to order at 8:35am.

An executive session was held at the beginning of the meeting. The work of Jerry Zoloto, the coach/facilitator was discussed.

Executive Director joined the meeting at 9:15 AM

Approval of minutes from January meeting: Melissa invited Board members to suggest any changes to the minutes. Laurel Rossi noted that she had a change to be made but needed to review her notes. Approval was tabled for further discussion .

Board Priorities: Tricia reminded everyone that it's important to build on the momentum of the Board retreat and establish priorities for 2018 in the areas of growth (development and member engagement) and succession planning. Tricia noted that we need to get as specific as possible and consider how we want to measure our accountability. If we are going to talk about these things monthly –we need to talk about our progress against our priorities at these monthly meetings.

### **Growth**

Cyndra reported out on the activities of the development workgroup and, in particular, two agencies who have suggested in depth organizational assessment as the best way to begin the development process. Board members were reminded that Terry had provided brief reports about each of the agencies prior to the January teleconference. Cyndra discussed the two development firms she interviewed, Graham Pelton and R&R. She talked about the deliverables from both firms and why it may be preferable to use a firm instead of hiring a development person immediately. Fees would be about the same between two firms, deliverables are similar. Terry spoke to one client from GP. The board discussed the preferred timing for when to hire a development staff person (for example, immediately vs. following the assessment). The board also discussed whether it would be preferable to pay a staff person while doing the development assessment.

Cyndra explained that Graham Pelton is a fairly large firm (38 staff) based in New York with additional offices in the US and Europe. Their organization assessment costs about \$50,000 and concentrates on the organization's "readiness" for donor development and the donor database itself. The 10 to 12-week process involves interviews with staff, Board members, major donors/stakeholders, a review of fundraising and donor recognition processes currently in place, and a donor database wealth assessment. WSA's former development director, Allison White is now a VP at Graham Pelton and would take the lead for an assessment of the WSA.

Richner and Richner is a much smaller (7 staff) organization based in Ann Arbor, MI. Their assessment is also \$50,000 and takes 4-6 months. R&R takes a more “organization-focused” approach and the actual donor assessment seems to hold a smaller priority. Richner & Richner was quick to tell us that ordinarily they would not be interested in working with an organization of our size but the partner has a niece with WS so he is willing to make an exception and would take the lead on the process.

Cyndra recommended, based on her background in fundraising, that even though its expensive, the WSA should undergo the assessment to help establish a plan for the eventual development director. She explained that turnover among dev. directors is quite high (every 2 years) and one prime reason for that is that companies tend to hire first and expect the DD to quickly acquire both the corporate and donor base knowledge needed to create and carry out a comprehensive development plan with aggressive goals. Often times, with this approach, after getting to know a company well enough to create a plan, the Director realizes the organization is not ready for a development strategy or the focus that is needed is not the current director’s specialty etc. Put simply, the assessment will help insure that we are setting up our eventual hire for success.

More discussion followed about the assessment process. It was explained that an agency has both the tools and the staff available to assess a donor base thoroughly and in a more timely manner than what one person could do. A question was also raised about beginning the hiring process concurrently with the assessment process. It was explained that part of the assessment report is suggestions for the type of person to hire and sample job descriptions, employment ads etc. Hiring before the assessment could be putting the “cart before the horse”. Additionally, the assessment will help provide us with the knowledge we need to insure accountability for the development director when hired.

What does accountability look like? It would be very helpful if we (the Board) could define development priorities and financial goals. “I don’t know, I just want to raise a bunch of money,” is not an effective strategy.

Marella asked what Graham Pelton knows about fundraising in the diversity community. It would be good to get an answer to that question before we begin the process.

Scott also wanted to make sure that we give whichever firm we retain clear targets and specific instructions concerning the deliverables. Scott offered to help with the negotiation process. Melissa asked Cyndra to pull in other Board members as needed.

There was discussion regarding the website privacy statement and the need for legal counsel to ensure that we are acting consistently with our privacy policy. . Laurel noted that there may also be a need for an “opt out” for our donors. The Board agreed that it was important for outside counsel to review and make a recommendation.

*Motion: to accept the minutes of the January 28<sup>th</sup> teleconference as amended to include the need for legal counsel to review and rewrite, if needed, the WSA privacy statement.*

*The motion was seconded and unanimously approved.*

*Motion: to move discussions with Graham Pelton forward toward engaging them to perform a full development assessment for the WSA. Cyndra will take the lead on the process and report back to*

*Board with additional details on the process prior to going to contract.*

*The motion was seconded and approved with 13 aye votes, 1 nay vote (Laurel Rossi).*

## **Membership**

There was a discussion about current membership and how we should define goals for growth. Terry was asked to describe the current membership and plans for expanding the membership. She explained that more than 5000 families have been or currently are members of the WSA, and that an issue with the auto-renewal process in our previous database [that we were not aware of] resulted in many of the expired memberships. Terry has put a program in place for 2018 to reach out to families with expired memberships as well as increase the number of new memberships. The WSA staff and RCs have created a comprehensive plan for increasing awareness and memberships with the distribution of materials to all hospitals/ISDs/Resource agencies etc in the vicinity of each RC and Committee member. Additionally Terry has secured a list of 2000+ attendees at the 2017 conference of the American Medical College of Genetics and Genomics for an additional mailing.

Following a short additional discussion on current membership and the potential for membership in the United States, it was suggested that a reasonable goal will be to “re-engage” 15% of the membership.

Terry was asked to add current membership statistics to every written ED report and have them available for each monthly call. She will also add a “how did you find us?” question to the membership application.

The Board discussed what a realistic 12 month goal would be, so that we can measure progress over the year. We need to revisit how to actively engage/maintain the 5,000 current members and find ways to engage the 25,000 we haven’t touched, many of whom may be undiagnosed. The Board discussed tracking year over year growth for membership, and trying to ascertain how members are finding the WSA. We also discussed that it may be helpful to have clear goals for how to reach: adults, children, underserved populations. Particularly interested in demographics of membership population vs. demographics of general WS population.

Terry also shared that the ICD code would now be available to the medical community.

Jocelyn and Carol are going to work together with Terry to gather info about membership and develop a smart goal for membership.

Laurel Rossi suggested that WSA retain a CRM consultant to help us understand what we can ask online and how. She will follow up with the member support committee.

## **Board Manual**

Melissa explained that the manual has been under review for a while and much of the update process is close to complete. She would welcome someone’s help with the final adjustments. Board members were encouraged to let Melissa know in the coming week if they are available and interested in helping. Matt volunteered to create an appendix to the manual in regard to record-keeping, and will work on creating a Slack channel that contains prior minutes for convenience (not to replace the official repository). [After the meeting, Jocelyn offered to help with the additional edits as well.]

Laurel noted that she would like to re-define the executive committee. Melissa explained that Executive committee structure is a by-laws amendment rather than a Board manual stipulation so while it is certainly an option, we would need to re-open the by-laws and have attorney review. Melissa will place on a future meeting agenda for further discussion.

### **Nominating Committee**

Laurel discussed the current process for election of officers (and ultimately the Executive Committee). She noted that the current process is for Board members to self-nominate or nominate others for each position. A question was asked about the policy of accepting self-nominations. After a short discussion it was decided that self-nominations were fine.

*Motion – to formalize the policy for officer elections as follows: Board members can be nominated for multiple offices, and self-nominations will be accepted. Each office will be elected by silent ballot with all votes counted in the room; votes will be announced after each position.*

*The motion was seconded and unanimously approved.*

### **Research Committee**

Jocelyn announced that Camille Fortunato has joined the committee.

WSA recently received the proposal we had been accepting from the MIND Institute at UC-Davis. The research team has requested a \$50,000 challenge grant to create a “distance delivered” social skills program for teens and young adults with WS. The group proposes to adapt a trial curriculum aimed at developing social interactions (conversation skills) within the Autism community to make it appropriate for those with Williams syndrome. It will be aimed at teens and young adults initially but over time will be adapted for younger children as well.

The committee recommends full funding of the request, noting that we (WSA Exec Dire and others) know the researchers and have great respect for their work.

Terry reminded the Board that funding the request will also require an amendment to the budget, as had been discussed at the Nov. 2017 meeting. She noted that the funding for the award and change to the budget can be handled through our retained earnings.

*Motion – to fully fund the MIND Institute request and adjust research spending in the 2018 budget to reflect the award.*

*The motion was seconded and unanimously approved.*

Jocelyn also noted that Camille had suggested that WSA create a “quick guide” for administering anesthesia to patients with WS that parents could have readily available for emergency situations. Terry has requested the document from the anesthesia team at Columbia but they are hesitant to create it until their current study is complete. She is currently working with BCH and Stanford as well, and hopes that the 3 teams will agree on a “best practices” document for distribution at the convention or soon after.

The research committee recommends that our current priority for a study on anxiety is still a priority. Jocelyn has drafted a parent survey aimed at getting Dr. McDougle the information needed to decide the best parameters for a study. She will send the survey to Terry so she can send it to Dr. McDougle for his input.

Marty has been in contact with healthychildren.org in regard to an article about Williams syndrome. The article will be aimed at parents but also seen by physicians who are regularly on the site. Marty and Jocelyn will work together to create the article.

Future goals of the committee include establishing a clear framework for research priorities and distributing RFPs for critical studies (such as anxiety); partnering with similar organizations and other bigger organizations where those partnerships can derive mutual benefits for each organization; establishing a young investigator grant (similar to the K award from NIH or Young investigator award from Marfan Association) to help promote lasting interest in WS among new researchers.

A suggestion was made to create a cross-committee work group on collaborations/partnerships...to identify which groups we should partner with in the immediate future, both within and outside of the research community. Terry suggested that Laura Chesser should be included to discuss partnerships in regard to state and federal resources. Cyndra suggested that Randy Cole would be willing to participate as well and Marella noted that we should be very thoughtful and targeted about with whom we enter into partnerships.

### **Awareness Month**

WSA should encourage all Walk Coordinators to speak about WSA at their events and present a call to action to participants. Terry will create 3 action points for each coordinator to add to their thank you remarks at their events. Registry and Membership should be 2 of the 3 topics.

For example: Are you a member – check your phone today! The Benefits of Membership include:...

Terry will send a list of all walks out to the Board members so they can decide which ones they will attend.

### **Convention**

Funding- Marty explained that he had received a request for scholarship funding for 3-4 families from Israel, and he wondered if there was funding to support them. Terry noted there have also been requests from folks in Sweden and if we fund the folks from Israel we should also fund the folks from Sweden. She also reminded Board members that we have received requests for \$72,000+ in funding from our members and committed to providing an additional \$23,000 in funding to the RCs.

Discussion followed about the benefit of bringing int'l org. leaders to our convention. Marty explained that the families in Israel are not the org. leaders. Terry noted that she has been approached on a few occasions to see if the WSA would be interested in organizing and leading a worldwide consortium for all the WS organizations. We have discussed the possibility at past Board meetings but no action has been taken. It would make more sense to invite all the leaders to come to the US to discuss the possibility of a consortium and what it might look like. The possibility was noted for future consideration. Funding will not be provided for int'l families to attend the 2018 convention. The Board further discussed that we should think about a more strategic international approach, and it should be a sub-point for membership goals.

Board reception– Melissa and Terry explained that traditionally there is a Board sponsored cocktail reception at the convention. It has been intended as a meeting to thank sponsors, major donors etc. This

year it would be nice to recognize a few members who have made a long-standing impact or done something extra special for the WSA as well. Discussion followed regarding whether it would be better to simply recognize those folks at the beginning of a general session or other “all convention” event. Terry was asked how much has been budgeted for the event in the past and she noted it was typically \$5000 – 8,000 depending on the location and size of the event. The evening event provides an opportunity for these folks to invite a few guests and attend something special – perhaps we could do both. Terry suggested that the WSA award recipients could also be acknowledged at the dance on Friday night which is always very well attended (800+). Terry & Melissa will prepare a list of attendees for review on the May video call and we can discuss the potential nominees as well.

*Motion: to approve the expenditure of up to \$10,000 for the Board recognition event.*

*The motion was seconded and unanimously approved.*

Board responsibilities at the convention - Board will wear “Ask Me” t-shirts and host a table in the exhibit area. Each committee chair should prepare an information sheet as handouts. Board table could also be a place where families could “find a friend” – Board members would be able to access the membership list and provide information for families who live nearby.

Breakfast with the Board – Attendees will be invited to have breakfast with the Board on Thursday morning – breakfast will take place in the main area with Board tables identified so folks can join a table to learn about the WSA’s strategic initiatives.

Carol suggested that individuals with WS should act as ambassadors at the convention- greeting families, introducing speakers etc. Ambassadors will be chosen ahead of time. Carol will spearhead the project.

### **Future Meetings/Board Business**

Scott had a question about financials. We say 14% fr and administrative (comes out of audit and 990. Includes all of the hours that go into projects). But in the budget it looks larger. What is the definition of the fundraising line expense? Scott said he will send an email detailing his questions to the Board.

Melissa and Carol noted that we need a high commitment level from the Board; everyone needs to be on every call. We will have zoom calls in **May, June, September, October at least**; action items will be at beginning of each call, then decision points, then action items at end.

Things that were to be discussed further at future board meetings included by-laws, board manual, board to be cost neutral for the organization, and opportunities for the Board to hear from the staff. Zoom video conference meetings will be held on the 2nd Monday of the month at 8 EST – May 14<sup>th</sup> at 8 PM; September 17<sup>th</sup>; October 8<sup>th</sup>. (no meeting in July or August). Monthly cadence will be re-visited after October call.

Terry will not be required to provide written reports for Zoom calls but will provide membership and financial highlights on each call.

Location for fall meeting – Board remembers were reminded that the plan was to have one meeting each year at an off-site location – perhaps Chicago, St Louis or Dallas (areas that are major hubs and provide easier travel options). There was a question about cost, and it was noted that Troy is considerably less expensive due to our ability to keep costs down with non-hotel-based meetings. Matt suggested that the Board should be “cost neutral” and if the Board would like to hear from WSA staff members as well, Troy is the best option. Melissa suggested that the Board go back to a full weekend schedule. Terry explained that for 20 years, meetings were always Fri at 6 to Sun at Noon. A change was made to eliminate Sundays about 8 years ago.

*Motion: to have the fall meeting in Troy and expand the meeting through Sunday at noon.*

*The motion was seconded and unanimously approved.*

The Fall Board meeting will be held November 9-11.