

## **WSA Board of Trustees**

### **Meeting Minutes - April 7-8, 2017**

**In attendance:** Aine Smalley, Melissa Murphy, Carol Patinkin, Jocelyn Krebs, Marty Levinson, Michele Self, Sarah Giddings, and Executive Director, Terry Monkaba. Dean Packard & Tricia Purdy-Messinger joined via teleconference. Laurel Rossi joined on Saturday. Jeff Baer, Marella Holmes, Seth Nicotra, and Kate Bierfeldt were absent.

**Teleconference Minutes:** The date of November 4/5 was confirmed for the Fall and it was decided that the Fall meeting prior to a convention year would be held in the convention location, and all other meetings would remain in Troy.

#### **Executive Director Report**

Transfer to a Salesforce database and Kimbia fundraising platform is ongoing.

**White Night:** The event will net more than \$500,000 for medical research. Discussion followed about the incredible outpouring of financial support at the event – truly inspiring for all who were in attendance and especially for the parents who were able to attend.

**Awareness:** as expected, the number of walks has decreased again this year. A suggestion was made to assign a few experienced walk coordinators as mentors for the new coordinators. Terry is working with Julie Hall and Rebekah Pagis to capitalize on media foundations that were laid leading up to Rare Disease Day and White Night. Efforts will be concentrated in the areas of the biggest walks.

**Camps:** Fist camp program for adults with WS hosted by Camp Blue Skies was very successful. The only downside of the opportunity is the cost – suggest local walk or event can be designated for camp expenses to bring the cost down for campers.

#### **Finance Committee Report**

Board treasurer, Jeff Baer explained the audit had been completed and the report he received from WSA auditors was unremarkable. No areas of the financial reports were noted as areas of concern.

Terry explained that the finance committee gets reports from our investment advisor, but since our advisors make all individual investment decisions based on our stated policy, we don't have a specific committee. Dean further explained that he has confidence in Planning Alternatives and their abilities. Their reporting is not as comprehensive as reports from other groups, but they are adequate for our organization.

#### **Development Committee Report**

Jeff explained that he had agreed to chair the Development committee and would like a large (~ 10 members) committee.

There was a question about formalizing the hiring of a Dev. Director. Members were reminded that we had decided a consultant is the best way to start.

#### **White Night**

It was noted that the event drew in over \$120,000 in corporate sponsors, most of whom are new to the WSA, and we must work very hard to cultivate the sponsors in the best possible way so they will become repeat/long lasting friends of the WSA. Discussion followed about the best ways to do that, and the possibilities that had been

## **WSA Board of Trustees Meeting Minutes - April 7-8, 2017**

discussed by the committee such as a cocktail party, personal calls/meetings by Board and E.D., follow-up mailings etc.

### **Research Committee**

Jocelyn discussed the 2017 research associated goals and progress on each of them to date.

- Terry has requested blog posts from Carolyn Mervis (educational testing) and Tom Collins (his new publication regarding peri-operative procedures. They are expected by May/June
- Jocelyn will create a webinar in early May to explain the BCH research in layman's language. The White Night committee has requested the webinar specifically but it will be great for anyone who is interested
- WS Clinic report of Best practices for care of patients with WS – we might need to provide some funding so a clinic director can put a staff associate on the project. With funding available we could put out an RFP to see if any clinic directors are interested in overseeing the project. Terry will provide contacts for the directors to Jocelyn. Jocelyn will also follow up with Colleen to see if she has a release date for the updated pediatric guidelines.
- ICD-10 for Williams syndrome - paperwork has been submitted. Marty will help if medical expertise is needed during the process

**WS Registry** – family participation continues to lag. Dr. Pober and Jessica suggest that it would be good to know if all family orgs. who have started registries have the same problem or if we are “missing the mark” in terms of marketing. Recent webinars and designated “registry day” did not do much to motivate folks. Webinars were poorly attended but folks know they were recorded and can be accessed at any time. Blogs have been written, and there will be another call to action now that the cardio and anesthesia studies are funded. What else can we do?

Melissa Murphy noted that she has a contact through Rose's endocrinologist to the CF registry. She will ask for information for us on all the things they do such as give-a-ways – i.e. sign up for the Registry and you will be in a drawing for camp or convention scholarships etc.

It was also noted that larger organizations have dedicated registry committees – we may need a dedicated committee to help with the marketing of the Registry – especially if it is a continuous need.

### **Research grant proposals**

BCH Proposal: Jocelyn reminded everyone that the BCH gift agreement was provided just before White Night, and is ready to sign.

### **New research grant requests:**

Bonnie Klein-Tasman (University of Wisconsin) has asked for a renewal of her study on behavioral play therapy for children with WS. She has requested \$100K a year for 2 years. The proposal has just arrived and committee members have not yet had a chance to review.

Carolyn Mervis (University of Louisville) has informed Terry that she will also be requesting a 2 year renewal of her grant for the longitudinal study.

### **Member Support Committee**

Carol and Melissa explained that have been developing committee objectives for 2017-18 as follows:

## **WSA Board of Trustees**

### **Meeting Minutes - April 7-8, 2017**

Increased access of members to Board members: the committee suggests that Board members do their best to attend walks – in particular those that WSA staff is not attending. Michelle explained that the Board members should not “quietly” attend. They are there as Board representatives and should wear the “Ask me” t-shirts and insist on helping the committee at the walk (at the registration desk, raffle table etc. where they will meet many attendees.)

Medical Outreach: Melissa explained that the committee feels a tiered approach is the most realistic expectation and can be very effective. The committee will connect with the WS Clinics first, then major medical centers; followed by as many centers as possible.

Regional Chair Support: Per previous conversations, a list was sent around the table so Board members could indicate they would like to call periodically to provide updates on WSA program, answer questions etc. Each Board member will call 2 RC's. Aine will send an introductory note to regional chairs announcing the new plan to help keep RCs informed of WSA Administration and policies via phone calls from a Board member several times a year.

#### **Nominating Committee**

Laurel will chair the committee. Tricia, Dean, Marella and Jocelyn (plus Aine & Terry) are also members. Laurel distributed a process document from one of the other Board's she is on to use as a starting point, noting that the document suggests a 12-week process.

It was noted that the process for electing officers also needs updating. Laurel suggested a success from Secretary to President as a possible structure, explaining that it works well for the Boards she is on.

The committee should prepare a current list of functional skill sets needed (and not provided by current Board members) on the Board. That will be important to the process on vetting new candidates. Tricia will oversee the functional skill set priority process.

Give or Get Policy discussion – Aine noted that some candidates, and nominating committee members have questioned the Board's current give or get policy of \$750. Following a short discussion, it was decided that the policy is reasonable and should not be changed or eliminated.

Board members were reminded that it is very important that we have 100% annual appeal participation from Board members. Participation can be at any level but it is important to be able to site 100% participation on grant requests etc.

#### **NEW BUSINESS**

##### **Convention:**

Keynote Speaker – Laurel will contact Dan Habib. He speaks on inclusion (in the Broad sense- not just at school) and is excellent.

Professional conference – Terry will ask the key researchers whether before or after convention is best for their meeting

Entertainment – Marty suggested that Baltimore is a good location for David Roth (came to convention in MN and was very well received). Marty will reach out to see if would be interested.

**WSA Board of Trustees**  
**Meeting Minutes - April 7-8, 2017**

Programming –

- Entrepreneurship class for adults
- “My Hero Brother”: Marty recommends that this film could be a great addition to the Convention program. It is especially great for siblings but everyone will benefit.
- Logo items - Tricia has contact for embroidery person who embroiders to order at events – she will get details for bringing them to next convention

Cost – Need to find way to offset hotel costs to families. We need ~\$100,000 to bring room cost down to \$139. Terry will begin investigating possible funding sources. Everyone else was encouraged to consider ideas as well.

**Upcoming Meetings**

There will be a teleconference meeting in June. Aine will send a doodle poll to determine the best date and time.

The fall Board meeting will be held in Baltimore on Nov 3 & 4.

**ACTION ITEMS FOR 2017**

- Terry will work with Julie Hall and Rebekah Pagis to capitalize on media foundations that were laid leading up to Rare Disease Day and White Night. Efforts will be concentrated in the areas of the biggest walks.
- Terry will work with Camp Blue Skies and local families (Atlanta area) to identify a fundraiser/sponsor to bring the cost down for campers so that program can be more accessible to families
- Development and marketing committees will be enlarged and 2017 goals will be determined
- White Night Video will special story cards will be distributed to donors
- Melissa and Laurel will determine “next steps” for insuring continued engagement of large donors
- Jocelyn will create a webinar to explain the BCH research in layman’s language.
- Terry will work with Barbara & Jessica to determine new ways to market the Registry (Melissa has contact at CF who might be able to help as well)
- Terry will continue to invite researchers to write guest blogs about their research findings
- Board members will attend walks and join the onsite volunteers to help at the events
- Sarah will create a Face Book Live implementation plan for social media marketing and information to members/potential members
- Tiered approach with dissemination of medical professionals will be initiated. Marty will send flyer to listserves
- Board members will identify 2 RCs and establish contact for periodic updates
- New directions will be determined for outreach to diverse populations
- Board manual to be updated and new draft presented in October
- Nominating committee process will be updated. List of required functional skill sets will be created
- FRAME (photos for medical community) – due diligence will be undertaken for possible inclusion of WS