

Williams Syndrome Association  
Board of Trustees Meeting  
November 9 - 11, 2018  
In person meeting, Chicago, IL

Board members present: Melissa Murphy, Jeff Baer, Jocelyn Krebs, Carol Patinkin, Cyndra Cole, Matt Bartow, Scott Ottenheimer, Alex Streit, Stella Beard, Marty Levinson,  
Laurel Rossi, Marella Holmes, Sarah Giddings  
Not present: Kate Bierfeldt

Staff present: Terry Monkaba

Meeting began at 1:00pm

Minutes approved: Jocelyn Krebs, Cyndra Cole 2nd

## Agenda

1. Finance Update: Jeff Baer
  - Investment Update: The WSA's investment policy is based on a conservative approach and allows for at 3.5% withdrawal. The board has the option to approve a larger or specific withdrawal. (Document attached)
  - There was a discussion of the fees for our investment group.
2. Review & Approve Budget (attached):
  - Specific topics discussed: raises & bonuses, new health insurance plan
  - Operating costs continue to be offset by income. Research funds are being supplemented by WSA reserved funds. The convention budget is separate per audit recommendation.
  - WSA will to continue to fund existing research and spend from reserve fund through 2019.
  - Potential impact on the 2019 budget: Development Director salary and increased fundraising.
  - General discussion on fundraising to be added to Sunday's agenda
  - Budget approved: Carol Patinkin motioned to accept the budget, the motion was seconded; 13 voted Aye, 1 No
3. New Business:
4. Executive Director Report (attached):
  - Highlights: Camp continues in Michigan, search continues for other camps that are affordable, near a hub airport, with appropriate cabins and general camp activities.
  - Registry:
    - Exciting new registry options: Backpack health app, Cyndra will follow up with Apple
    - Growth continues to be slow; some obstacles discussed included the parents need direct WSA staff help to get through the registration process. Should there be a WSA staff member on the Registry team?
  - The website needs to be overhauled. The funds are not currently in the budget. This is a critical need.
  - The NIH Conference is being held at the same time at the Neuroscience conference. Jocelyn will follow up with researchers regarding this conflict.
5. Development Director Search Update: Cyndra and Terry

- The Job was posted: 20 were reviewed in first phase.
  - The Search Committee is in the process of 5 in-person interviews.
6. Nominating Committee—Slate of Proposed New Trustees: Laurel
- The slate of 4 new board members was unanimously approved.
  - The nominating committee will call all applicants prior to WSA membership email with slate information.
  - Committee expansion and exec committee discussions moved to Sunday's continuation of board meeting.
7. Executive Session
- Meeting adjourned at 4:30 PM

Sunday, November 11th, meeting reconvened 8:00am

8. Committee assignments moved to January Agenda
9. Executive Committee Expansion Discussion:
- Addition of the monthly board zoom calls and the president's quarterly email updates have had a positive impact on communication.
  - Unanimous decision not to expand the Exec Committee
10. Executive Committee Elections
- Final Slate approved:
    - Jocelyn Krebs for President
    - Cyndra Cole for Vice-President
    - Stella Beard for Secretary
    - Scott Ottenheimer for Treasurer
11. Other Business:
- Laurel discussed Accenture study about employment issues
  - Also, discussed: Sub-minimum wage concerns, Able accounts
  - Melissa & Laurel will explore WSA policy & advocacy partnerships, WSA role in Hill day, setting up a committee around policy and advocacy. There will be a Board briefing on Employment issues at the January meeting
12. Development discussion:
- Annual Board appeal: 100% participation required
  - Each board member will receive 20 annual appeal letters to send with a personalized letter to their possible donors.
  - WSA will send Annual appeal letter the week after Thanksgiving
  - Board recommended and agreed the WSA will send a Holiday Card with "soft appeal" (pledge card but no ask) to White Night Donors.
  - Holiday Card will be sent to members to arrive by 12/6 (to arrive curing Chanukah and before Christmas). In future years, Thanksgiving cards will be sent instead of Holiday cards.
  - WSA will track donors by specific appeal.