

SOTOS SYNDROME SUPPORT ASSOCIATION

Minutes of the July 11, 2010 Annual General Meeting

Minutes of the Annual General Meeting of the Members of Sotos Syndrome Support Association held at the Sheraton Arlington Hotel, Arlington, Texas, on Sunday, July 11, 2010 at the hour of 9:10 a.m., Central Standard Time.

Constitution of Meeting:

Donna Costello, the President of the Association, took the chair and called the meeting to order. Kristin Gilbertson, the Secretary of the Association acted as Secretary to the meeting.

The Chairman reported that there was a quorum of members in attendance at the meeting and stated that due notice of the meeting had been given to all of the members and as a quorum of the members was present in person, the meeting was duly constituted for the transaction of business.

Minutes of Last Annual Meeting:

The Chairman notes that the minutes of the last annual meeting of members held in Salt Lake City, Utah on August 2, 2009 had been posted on the website, published in the newsletter and additional copies were at the back of the room and therefore it was not proposed that the minutes be read. On motion duly made by Mike Jennings, seconded by Dennis Morris and carried, it was resolved that the reading of the minutes be dispensed with and the minutes as circulated be approved.

Chairman's Welcome:

The Chairman then welcomed the members to the meeting and thanked them for attending. She advised that there were some past presidents of the Association attending this meeting and introduced to the members Ed St.Clair, Jeff Cupps and Joanne Weick.

The Chairman then introduced to the meeting a number of the other officers, board members and committee members of the Association and thanked them for their diligent work during the past year.

Treasurer's Report:

The Treasurer, Joanne Weick circulated copies of the Financial Statement and presented the Financial Report for the Financial Year ended 12/31/09. At December 31, 2009, the organization's account balances were \$125,766.69. Of this \$57,960.83 is in the William's Family Technology Fund. Kevin and Toni Williams created this fund and receive donations to fund technology projects to educate and support our members and the public. The production of the DVD, "What is Sotos Syndrome?" was their first project.

The Treasurer went on to explain that the Carol Richey Fund was set up to honor one of the founding members of the SSSA. The income from this fund is to be used to provide financial assistance to families who are attending the conference for the first time. This year the fund provided assistance to seven families to attend the conference.

The Treasurer noted that a number of donations were received throughout the year that contributed to the Association's general operating fund and the Carol Richey fund. Some examples of this included a fund raising event that was held by Ohio members, Ken Rupert's donation of a percentage of his coin sales thru Mission Fish, Guy Peret's donation of the cost of maintaining the SSSA's website Domain and the William's family donation of the cost of printing and mailing out the

newsletter. Joanne explained how donations thru the United Way can be earmarked for the SSSA, and if you want more information on how to set this up you can e-mail her. The Treasurer also noted that using the Good Search web browser tool is another way you can easily raise money for the Organization. Carolyn Gregory explained to the members that for every Search made thru Good Search, they will donate one penny to the SSSA and if you shop online thru Good Search, they will donate a percentage of the sale directly back to the SSSA.

On motion duly made by Richard Costello, seconded by Ed St. Clair and carried, it was resolved that the Treasurer's report be approved.

Membership Report:

Lisa Cruse then presented the Membership Report for Kieanitria Paschal who was not able to attend the conference. There are currently 249 current members, of which 133 were current with their dues and 107 have not yet paid for 2010. There have been 85 new contacts in the past year. There have been 27 new members since the beginning of the year and 59 in the year prior. There are 54 families in attendance at this 2010 conference.

Website:

The Chairman recognized Guy Perets for the work he has done on the SSSA website. She explained to the membership that a website committee was being formed and that BJ Cupps has stepped forward to help. The committee members would review the internet website and make sure it's content is current. Ed St.Clair also volunteered to be on the committee.

Advisory Board & Family Database for Research:

The Chairman recognized the Advisory Board's members and thanked them for their service to the Organization. The Advisory Board consists of Rebecca Anderson, Dr. Trevor Cole, Dr. Peter Heydemann, Dr. Brett Kuhn, Dr. Bruce Buehler and Dr. Brad Schaefer. Donna noted that the results from last year's sleep study survey will be posted to the website and published in an upcoming newsletter.

Newsletter:

The Chairman stated that the Board has decided to reduce the number of issues of the SSSA Notes from four issues to three issues. This decision for three yearly issues beginning with the February 1, 2011 issue, followed by June 1, 2011 and October 1, 2011 was agreed upon at this weekend's board meeting. It was also agreed upon at the board meeting that the October 1, 2010 issue will be the last hardcopy issue published. The February 1, 2011 issue will be posted online and only those members who do not have e-mail addresses will receive it by mail.

The Chairman noted that at this time, Carolyn Gregory solicits newsletter items and Richard Costello handles the layout. Many members are reading the newsletter by a show of hands though some people are not getting the e-mail blast that announces that the newsletter was posted to the website. Keith Eliasson stressed that more frequent communication needs to be given to the members and volunteered to be on the website committee.

On motion duly made by Mike Jennings, seconded by Richard Costello and carried, it was resolved that the committee reports be approved.

Action Items:

The Chairman explained that a By-Law Revision Committee has been created to review the Association's current by-laws as it had become apparent that they were no longer adequate to serve our long-term needs. This committee was made up of board members, one officer, one member at large and outside volunteer legal counsel. A copy of the committee's letter

was then distributed to those in attendance at the General Meeting. The letter explained why the revisions were made and what they were.

The Chairman opened the by-law committee's revisions for discussion. Kevin Williams, a by-law committee member explained that it is necessary for not for profit organizations to stay compliant with IRS laws and with Missouri's laws. He noted that no changes of financial control were made in the revisions of the by-laws. The Chairman reviewed some of the by-law revisions and noted that there were three classes of membership; family, individual and honorary members. A family membership would have one voting right, an individual membership would have one voting right and honorary members would have no voting rights. Donna explained that the President will be on the board automatically and that board members can only serve for six years maximum with 2 consecutive three year terms. Richard Costello, a by-law committee member noted that the board was given the ability to create committees to broaden infrastructure. Kevin Williams, stated that the revised by-law enables the board to borrow money and allows for overdraft protection, and the ability to lease equipment and open up lines of credit. The Policies and Procedures committee will address what types of borrowing would be allowed.

On motion duly made by Richard Costello, seconded by Mike Jennings and carried, it was resolved that the discussion of the by-law committee's revisions be closed. On motion duly made by Ed St.Clair, seconded by Richard Costello and carried by a show of hands, it was resolved that the First Amended and Restated Bylaws of Sotos Syndrome Support Association be approved.

The Chairman then stated it would be in order to elect directors for the year. There are six current board members who have expired terms. They are Stephanie Anderson, Karen Duffin, Bryan Shelhamer, Andrew St. Clair, Carrie Leddy and Michele Harding. Donna thanked them for their service. There are four director positions to be filled at this meeting. The President opened the meeting for nominations. Stephanie Anderson, Andrew St.Clair, Carrie Leddy and Bryan Shelhamer were nominated.

There being no further nominations, a motion was made by Mike Jennings to accept those nominated as elected directors to hold office for the ensuing three years and to close the nominations. The current board members were announced. Jan Hilton seconded the motion and by a show of hands the motion was approved.

Conference Reports:

Monica Boers reported that next summer's SSSA Conference would be held at the Marriot Hotel in Williamsburg, Virginia on July 29 - 31, 2011. The families organizing the conference are the Ruperts, Siers and Wyricks. The hotel's room rates are reasonable and there are three different airports nearby. There are many attractions available to help make your stay enjoyable, including Busch Gardens, Colonial Williamsburg and Water Country USA.

Proposal for the 2012 conference site is Vancouver BC, Canada. Jan Hilton has agreed to plan it but solicits help from other members who live in the area. A possible location for 2013 would be Orlando, Florida. The Jennings family has offered to help plan it if this site is chosen.

The Chairman reported the conference numbers for this weekend as Michele Harding was not able to attend the conference. There were 33 families re-attending and 21 new families attending. This broke down to 104 adults and 52 children. She noted that this year there were approximately \$20,000 in registration fees and the Silent Auction raised approximately \$2,300.00. Donna explained that the proceeds from the Silent Auction are used to assist families in attending our annual conference thru the Carol Richey fund. She noted that the highest expense for putting on a conference is paying for the meals and though child care is usually very high as well, this year's child care staff was voluntary. The conference budget was reduced because of these many types of donated goods and services. She went on to explain that without this supplemental income, our registration fee would have been \$200.00 per person instead of the 'early bird' fee of \$125.00 per person.

The Chairman asked the conference attendees to complete the conference survey forms and turn them into a board member or conference organizer. She thanked the Swafford family for their work in organizing the 2010 conference.

Announcements:

The Chairman thanked Saul Arteaga for his help in translating the SSSA tri-fold into Spanish. Saul also helps translate Spanish e-mails we receive.

Mike Jennings noted that this was Donna's last meeting as President and thanked her for her service to the Association. Donna introduced Monica Boers as the new president of the Sotos Syndrome Support Association and announced that the next General Meeting would take place in Williamsburg, Virginia on July 31, 2011.

Termination:

There being no further business to come before the meeting, on motion duly made by Carolyn Gregory, seconded by Mike Jennings, and carried, the meeting terminated at 10:35 a.m..

Chairman (Donna Costello)

Secretary (Kristin Gilbertson)