



THE CHROMOSOME 18

REGISTRY & RESEARCH SOCIETY

Responsibilities of the Syndrome Coordinator

1. Syndrome coordinators will moderate the syndrome Message Boards to be sure the discussions are positive and a source of strength and information for members.
2. Syndrome coordinators will moderate the syndrome breakout sessions at the annual family conference (if attending) to be sure the discussions are positive and a source of strength and information for members.
3. Promote and communicate information to your syndrome families, regarding all Registry organized fundraising events. This includes direct emails and regular postings on our social media sites (Facebook & the Message Boards) regarding Registry fundraising events, up and until the day of the event.
4. See that at least one educational event is presented each year (lecture, health fair exhibit etc.; examples of lectures can be to a school group, church group or professional organization).
5. Syndrome coordinators will be aware that they are ambassadors of the organization at all times and lead by example.
6. Syndrome coordinators will encourage others to participate in organizational functions such as conferences, get-togethers and fundraisers.
7. Coordinator will send welcome note of introduction to the new families.
8. Report at full Board of Directors meetings on syndrome group activities of the past year.
(This may be done in person, by proxy or by written report.)
9. Failure to accomplish these goals will indicate the coordinators desire to resign the position.