

SILVER RUSSELL SYNDROME GLOBAL ALLIANCE CONSTITUTION AND MEMBER AGREEMENT

NAME Silver Russell Syndrome Global Alliance (SRS Global Alliance)

WHO WE ARE- Silver Russell Syndrome Global Alliance is a network of patient support organisations and medical professionals throughout the world who support patients (children and adults) who have Silver Russell Syndrome [Russell Silver Syndrome].

MISSION STATEMENT - The Alliance's primary mission is to contribute to the worldwide standardization of information on the clinical and molecular diagnosis, and the treatment management guidelines, of SRS. By connecting patients, families and medical professionals throughout the world to patient-support organisations in their local geographic areas, up-to-date diagnostic and therapeutic strategies will become more readily available.

OVERVIEW - MEMBER ORGANISATIONS – Membership is open to any patient support organisation supporting patients with Silver Russell syndrome. Patient support organisations may be nonprofit organisations, patient-based organisations or informal online support groups. No fees or dues will be charged to groups for membership. In the future, the Alliance may wish to seek donations from members to support new resources but donations would be optional and not mandatory. Member groups will be listed online sorted by country, with the ability to provide links to the member homepages. Members will also have permission to link to the SRS Global Alliance website from their own websites. The Alliance website information may be able to be used in a member organisation's own website or educational tools, but prior permission **MUST** be requested (some content is proprietary to either the Alliance or other sources and can not be copied or reproduced).

MEMBERSHIP PROCESS –

- The SRS Global Alliance will be constituted by a voluntary collaboration of organisations, each of whom applies for membership and agrees to the Alliance's mission statement.
- A membership application is made via submission of a simple on-line form.
- Applications for membership will be determined and approved by the Management Committee Chair and Co-Chair and at least one of the Medical & Scientific Committee .
- A member may be a non-profit organisation, a patient-based organisation or an informal online support group – but must be focused on supporting patients with Silver-Russell Syndrome and/or their families.

BENEFITS OF MEMBERSHIP –

- Access to up-to-date medical information on SRS written for two target audiences – patient/families and medical professionals;
- Permission for a member organisation to link the Alliance website to their own website to provide its own families up-to-date information;
- Ability for patients or families searching the Alliance website to connect directly to the member organisation in their geographic area;
- With requested permission from the Alliance, the ability to use some website information verbatim in a member organisation's own website or educational resources [unless otherwise noted or permission denied];
- Contribute towards a stronger united global voice allowing for more concentrated efforts in pushing for more breadth and depth into research and education related to SRS
- Ability to share successful strategies between organisations on how best to support local families and learn from each other;
- Strength in membership numbers helps the Alliance in any efforts to receive grant funding from outside organisations for key projects.

MEMBERSHIP WITHDRAWALS and EXPULSION –

- A member organisation may leave the Alliance at any time.
- A member organisation may be expelled with a two-thirds majority vote of the Management Committee for actions which are in direct conflict with the mission and goals of the Alliance, illegal activities, plagiarism of Alliance content without permission, actions taken to financially benefit the member which is to the detriment of one or more other members, or for causing conflict internally within the Alliance.
- In certain cases, a member organisation's representative may be banned from participating in the Alliance (and may be liable for other sanctions as well) for taking any of the above actions while the member organisation be placed on probation but not expelled. This decision would also require a two-thirds vote from the Management Committee.

FUNDING OF ALLIANCE –

- The Alliance will not require any membership fee or dues from its members.
- The Alliance will not seek on-line donations from individuals/families; the Alliance should therefore not compete against its member organisations in terms of funding or donations.
- Key projects taken on by the Alliance may be funded through grants from industry or foundations.
- The member organisation(s), when doing work on behalf of the Alliance, or representing the Alliance, shall work for the benefit of the entire alliance and not pursue its/their own commercial goals.

MEDICAL & SCIENTIFIC ADVISORY BOARD –

- The board will be made up of volunteer medical and professional specialists experienced in treating children with SRS or IUGR/SGA.
- The advisory board members will be selected by the Alliance Management Committee with a majority vote. The goal would be to have 1-2 specialists per country or geographic region.
- No membership fees or dues will be required from any board member. The position is a volunteer position.
- Each board member would serve a 12-month term and may renew for additional terms.
- The board members would be expected to answer electronic or phone communication from other physicians in their country/region who are seeking professional advice.
- The “Grounds for Member Expulsion” apply to members of the Medical & Scientific Advisory Board.
- The Medical & Scientific Advisory Board will be chaired by Irène Netchine, M.D. and Thomas Eggerman, M.D. for the first twenty-four (24) months. At the end of the 24-months, an election will be held in which chair candidates can be nominated from a pool comprised of any board members or current chairs. The two new chairs will be elected with a two-thirds majority vote of the Board members and all candidates may vote.

MANAGEMENT COMMITTEE –

- The SRS Global Alliance Management Committee will initially be made up of the following members:
 - One Chair – Nick Childs, CGF
 - One Co-Chair – Jennifer Salem, MAGIC Foundation’s RSS/SGA R&E Fund
 - One representative from the following patient-support organisations
 - Jenny Child - CGF
 - Dayna Carney - MAGIC Foundation
 - Benedicte Perotin - AFIF
 - Nonjia Rosen - ALICE
 - Klaus Mohnike, M.D. - BKMF
 - Two representatives from the Medical & Scientific Advisory Board
 - Irène Netchine, M.D.
 - Thomas Eggerman, M.D.
- The chairs’ elected term will run for one calendar year and can be re-elected for multiple years. Chair candidates will be elected from a pool comprised of the chairs and representatives currently in place, and shall be elected with a two-thirds majority vote of the Committee representatives from the patient support groups as well as the Advisory Board representatives combined. The nominees may also vote.
- There is no term length for the Committee Patient-Support Organisation Representatives – these five organisations are the founding members and until they can no longer participate, they are life-long organisational members. However, an organisation may choose to substitute in a new representative.
- The Management Committee may choose to expand the number of representative members of its Committee in the future, with a two-thirds majority vote.

- As such, at any time, an organisation may request to be a member of the Committee and accepted with a two-thirds majority vote.
- If one current organisation can no longer participate on the Committee, the Committee members may choose to substitute in a new member organisation with a two-thirds majority vote.
- If either of the two Advisory Board members on the Committee should choose not to participate any longer, a replacement will be made based on recommendations and a two-thirds majority vote from the Management Committee as well as the Advisory Board combined.
- The Committee shall attempt to handle the majority of its voting and correspondence via email.
- All communication pieces produced by the Alliance (either on the website or linked documents) must be approved by the Committee Chair and Co-Chair as well as at least one of the two Medical & Scientific Advisory Board members.
- A Committee chair or Committee member may be considered for termination based upon actions contrary to the mission statement, goals and rules of the Alliance and a majority vote of the Committee. This Committee chair or member shall not be allowed to vote in the decision regarding their discipline.