

## Rett UK Patron Role Description

### About Rett UK

Rett UK was founded in 1985 by a mum, Yvonne Milne, who became our first Honorary Chair when an Executive Committee was formed and charitable status obtained.

### Our vision is:

- That everyone with Rett syndrome is diagnosed, their symptoms effectively treated and their families, carers and friends inclusively and appropriately supported;
- A cure for Rett syndrome is found.

### In line with our vision, Rett UK's strategic aims are to:

- Deliver excellent support services to meet the short and long term needs of the Rett community;
- Promote, support and encourage research to enable improvements in identifying new therapies and treatments for Rett people and ultimately a cure;
- Raise awareness of Rett syndrome and its effect on individuals and their families;
- Pursue a broad range of funding opportunities in order to deliver our objectives.

### Overview of the purpose of the role

Rett UK would like our Patrons to support our goal of increasing the reach and scale of our work. We wish to establish a strong and select group of influential individuals as Patrons who have a passion for our work and have the potential to open new doors not just to help raise funds for Rett UK but also to raise awareness.

There is not an expectation that our Patrons give money directly to Rett UK themselves, but that they are able to identify and support introductions which may lead to funds being donated. It is hoped that Patrons will facilitate new corporate partnerships and relationships with potential major donors.

Patrons roles are flexible but there is an expectation that each Patron will attend one event per year on behalf of Rett UK, which may involve talking about our work. It may be on occasion that TV and Press reporters might be present. Rett UK will provide a briefing beforehand about the event and the audience.

As an 'influencer', Patrons should be happy to speak to the press and TV and use social media to help raise awareness, spread campaign/appeal messages and encourage others to become involved.

Patrons are not expected to attend trustee meeting or have an input to strategic development unless this was of particular interest to the individual concerned.

### *Role Description*

- Commitment and enthusiasm for Rett UK and its objectives
- Willingness to promote Rett UK where appropriate opportunities present themselves in the course of their everyday roles
- Ability to communicate effectively and passionately to a variety of audiences

### *Additional Information*

Patrons are unpaid, although reasonable out-of-pocket expenses will be met.

### *Relationships*

Patrons will be supported by the CEO and the office manager. We will provide information about Rett UK and the opportunity to meet people with Rett syndrome and their families. We will keep Patrons up-to-date with developments that relate to our work and the community we work with.

As a UK registered charity that provides services for public benefit we have to be conscious of the charity's reputation and need to comply with both company and charity law. If a Patron was operating outside of the law in any capacity either on a personal or professional level, or they did something that could be deemed to be detrimental to the good name of the charity, Rett UK reserves the right to end the relationship with the Patron.

(Enclosures will include - Annual Report, Latest Newsletter, Business Plan, Family Stories)