

## 1 The Policy

- 1.1 The aim of this policy is to provide guidelines for staff, trustees, volunteers and members of Rett UK. It is important that staff in particular are aware of the policy and ensure that it is implemented. These guidelines apply to anyone working in any capacity for Rett UK, including volunteers.
- 1.2 Rett UK maintains information records for individuals and groups and it is important that the people concerned feel confident that the information held is handled in an appropriate manner. It is also necessary for staff and volunteers within the organisation to know that information about themselves is kept within the bounds of the Confidentiality and Information Sharing Policy.
- 1.3 Information is confidential within Rett UK on a 'needs to know basis' between the enquirer and staff member or volunteer.
- 1.4 These guidelines will be updated in the light of experience and legislation and will be reviewed on a regular basis.

## 2 Policy Statement

- 2.1 The following points of principle make up the Statement on Rett UK's Confidentiality and Information Sharing Policy:
  - 2.1.1 The confidentiality of all information relating to people with Rett syndrome and organisations or individuals associated with Rett UK will be maintained at all times unless there is immediate and serious threat to the safety or welfare of a child or adult with Rett syndrome or their sibling.
  - 2.1.2 For the purposes of this policy, 'confidential information' will include all information which is identified or treated by the Rett UK as confidential or which by reason of its character or the circumstances or manner of its disclosure is evidently of such a nature. Without prejudice to the generality of these details, this will include:
    - database of member and non-member information
    - donor information
    - Disclosure information and related personnel details
    - research funding details
    - management accounts
    - any computer print-outs and analyses
  - 2.1.3 Rett UK reserves the right to withhold any payments due until all confidential information is returned. This action does not prejudice Rett UK's right to recover this information by legal proceedings.

- 2.1.4 The restrictions contained in this statement shall cease to apply to information which may otherwise than through default of anyone working in any capacity for Rett UK, including volunteers, become available to the public generally.
- 2.1.5 Any information kept about staff, prospective staff, volunteers and members must be stored in a secure place and be available, by arrangement, to the persons concerned.
- 2.1.6 Discussion between members of staff about personal circumstances of members, volunteers, staff and other relevant people will be confined to those relevant members of Rett UK .
- 2.1.7 Rett UK will only use family histories and photographs with the specific permission of the family concerned, which will be sought on each occasion. In seeking permission Rett UK will explain fully the purpose for which a family history/photographs will be used. For example, whether such intended use is:
- educational
  - related to a campaign
  - part of a report to an Rett UK funder
  - general publicity
  - for internal Rett UK use only

Rett UK will seek to avoid the exploitation of families and people with Rett syndrome and will offer appropriate advice to parents on handling the media with the possible long-term implications and consequences.

- 2.1.8 Rett UK has policies related to Equality and Diversity and Health and Safety. All staff also have contracts of employment. Any statements or actions which contravene or jeopardise these policies will fall outside the remit of the Confidentiality and Information Sharing Policy.
- 2.1.9 Members of staff will come across information about people with Rett syndrome and their families, professionals, other members and members of staff whilst working for Rett UK. All staff are expected to observe the confidential nature of such information and not to disclose such information outside of work.
- 2.2 The following guidelines will help staff to make decisions about the nature of confidential information and the place to share such information. In many instances staff will have to make judgements about confidentiality on a day to day basis. Staff may wish to discuss certain situations with their line manager, before making such judgements.
- 2.3 All confidential files must be kept in a locked filing cabinet. If they are stored digitally, they must be password protected.

### **3 Record Keeping**

- 3.1 Records within Rett UK are kept in various ways e.g. filing cabinets, databases, box files. The following guidelines apply to records of all types.
1. Records are common to all staff to whom they are purposeful and no others.
  2. Records about families should be kept up to the point where a parent requests that records should no longer be kept.

3. Rett UK has a responsibility to maintain records of staff and volunteers who have worked for it. These records must be kept in a locked filing cabinet at the office. Records will be kept for the period of time as provided for in legislation. (See Retention of Documents Policy)
4. Rett UK may retain statistical information which does not reveal the identity of the individual or group concerned. Statistical information should be kept separately from individual or group records.
5. Care must be taken at all times to ensure that all records are handled with discretion and are secured when the office is not occupied by Rett UK staff.
6. Databases should be protected by passwords known only to relevant members of staff.
7. The Chief Executive of Rett UK is the Data Controller and The Office Manager is the Data Protection Officer of Rett UK They will be consulted on all matters relating to database security. The Chief Executive is responsible for regular revision of data protection implications along with the board of trustees who also have a Senior Information Risk Owner.
8. Questions used on forms for record keeping need to be justified through line management and through discussion with individuals, members, staff and volunteers.
9. When paper records become redundant they must be destroyed in a secured and confidential manner.
10. When database records have become redundant they must be completely removed from the computer memory.

#### **4 Membership Records**

- 4.1 Membership records will be updated on a regular basis. This would normally be when a member notifies the office of a change of address, for example, or there is an external influence e.g. change in data protection regulation that necessitates a complete update of membership records.

#### **5 Reports by Medical Advisers**

- 5.1 The report written by medical advisers following a therapy clinic, the 'primary care record', must be complete. It will include (1) notes taken by each team member in individual consultations (2) the final report (3) notes of all follow up contact (written, verbal or e-mail).
- 5.2 The report will be kept at the Rett UK office in a locked cabinet or if scanned digitally, password protected.
- 5.3 Rett UK will send the report to the family. The family will circulate it to other professionals as appropriate

#### **6 Supervision**

- 6.1 It is Rett UK's policy that supervision is confidential within the line management structure. The purpose of supervision is to support staff and to ensure that the aims and objectives of the organisation are carried out. It is a time for the supervisee to discuss issues or problems at or affecting their work within this context.
- 6.2 The supervisor may have to bring certain issues raised in supervision to her/his supervisor or to other relevant staff after consultation/discussion with the supervisee.

6.3 Staff appraisals are confidential to the individual being appraised, the individual carrying out the appraisal (appraiser) and the appraiser's line manager, who countersigns the appraisal. The original appraisal document will be placed on the staff member's personnel file. A copy will be given to the individual being appraised.

## **7 Staff Team Meetings**

7.1 Staff meetings are a forum for exchanging general information and sharing ideas and are not confidential. Minutes are taken and circulated to the honorary chairperson. The minutes should be agreed at the following meeting.

## **8 Executive Committee Meetings**

8.1 The executive committee minutes are open to all staff and members to see. Anything of a confidential nature will only be circulated on a needs to know basis. Confidential minutes will be password protected. The password will only be known to the CEO and the Chair of Trustees.

8.2 Copies of minutes of trustees' meetings signed by the chairperson will be stored at the office.

## **9 Staff Personal Files**

9.1 The following information will be kept on staff files:

- a) Application forms and disclosure information
- b) References
- c) Medical notes
- d) Appraisal Forms
- e) Training Record
- f) Official letters e.g. to or from the director / honorary chairperson / external agencies
- g) Disciplinaries or grievances either as witness or appellant.

9.2 All personnel files are kept in a locked filing cabinet at the central office.

9.3 All staff have access to their own personal files. Access will be given on request. Referees and others will be informed of Rett UK's open access policy. If a member of staff disagrees with the content or tone of something in the file a note may be attached to the file giving the member of staff's perspective/reasons/concerns.

9.4 Line managers may have access to files of all staff for whom they are responsible.

9.5 References written for staff by Rett UK will be available in staff files.

## **10 Volunteer Records**

10.1 Rett UK has a responsibility to maintain records of volunteers who have worked for Rett UK .

10.2 All records relating to individual volunteers will be kept in a locked filing cabinet. In particular this relates to application forms, references and relevant correspondence.

- 10.3 If any volunteer picks up information which they think may be relevant to the welfare and safety of a child, parent, fellow volunteer or Rett UK member of staff, or which they think could seriously damage the reputation of the charity, they must contact the director or honorary chairman.

## **11 Theft of Records**

- 11.1 Should confidential records (either digital or paper copies) be stolen as the result of a break-in, the report to the police should clearly stress the confidential nature of the records and the importance of their being unread if recovered.
- 11.2 A written record should be made, detailing the circumstances and specifying the period covered by the stolen records.
- 11.3 Where the records have not been stolen but where an intruder could have examined them, a similar record of the circumstances should be made.
- 11.4 All line managers must be informed at the earliest opportunity of any break-ins and information that might have been stolen.

## **12 Staff Disclosing Information**

- 12.1 Staff must only disclose information about individual parents/carers and or groups if consent has been obtained from that individual parent/carer or group (or unless required by child and adult protection authorities).
- 12.2 Information concerning the welfare of an individual parent or group must only be shared with the relevant line manager or appropriate Rett UK colleagues.
- 12.3 Staff members in receipt of personal information from other staff must not pass this information on without express permission from their line manager.
- 12.4 Confidentiality / privacy of staff and volunteers must be maintained at all times.

## **13 Abuse**

- 13.1 All potential incidents and allegations of abuse must be taken seriously by Rett UK staff and volunteers. In this context abuse will mean children or adults who have Rett syndrome or their siblings who are suffering from physical, sexual or financial abuse or those suffering from consistent emotional abuse or neglect.
- 13.2 Any Rett UK representative discovering alleged or actual abuse will contact the Chief Executive as soon as possible. If the person discovering the alleged or actual abuse is a volunteer they must inform a Rett UK member of staff who will then inform the Chief Executive.
- 13.3 The Chief Executive and staff concerned will meet as soon as possible to discuss the most appropriate way of handling the situation.
- 13.4 The person discovering the alleged or actual abuse will record in a written form the circumstances in which the information was disclosed or discovered.

- 13.5 Staff and volunteers will be expected to maintain complete confidentiality in cases of alleged or actual abuse. Communicating facts or allegations to authorities outside Rett UK will be the responsibility of the Chief Executive.
- 13.6 If, in the opinion of staff concerned, the person's welfare is at extreme and immediate risk then the relevant Social Services department will be notified immediately. For these purposes 'families' means those who have Rett syndrome, their parents, carers and siblings.

Related policy:

- Retention of Documents Policy
- Policy on Handling DBS Disclosures.
- Safeguarding Children, Young People and Vulnerable Adults Policy
- Data Protection Policy