

## **MECFS SOCIETY YOUTH POLICY**

The ME/CFS Society (SA) inc. acknowledges the unique difficulties young people with ME/CFS Experience.

- 1) Socially formative years are interrupted – need to address confidence and socialization issues
- 2) Social Isolation
- 3) Difficulty in completing their education
- 4) Self Esteem

### **YOUTH INCLUSION IN EDUCATION POLICY**

Individual members of the society have long identified the need for young people to receive educational services, which are equitable and non-discriminatory. To this end a pro-active school inclusion policy is being promoted. It is hoped that an improved outcome in terms of curriculum and flexible school attendance will be created.

### **MISSION STATEMENT**

The society aims to promote:

- Community understanding of chronic fatigue and the effects of the illness on young people and their families, and social and educational experiences.
- The society will also seek to advocate on behalf of its members, to obtain equitable outcomes for them in the above areas.
- It actively promotes a policy of INCLUSION, in the sphere of educational opportunities.
- The CFS will seek to support its youth membership, by creating opportunities for achievement and recognition.

## **GOALS**

### **I. IMPROVED ACCESS TO EDUCATIONAL FACILITIES**

The basis of our INCLUSION policy is to encourage educators from both government and non-government/independent sectors to become sympathetic to the needs of young people with CFS. This includes a readiness to understand the condition and the disruptive effect it may have on ongoing schooling. We would like young people to have educational choices, and the opportunities to attend mainstream schooling as well as Open Access Schooling. We would like young people to be supported by flexible policies that allow children to combine open access studies and mainstream schooling backed up by the availability of counseling in the choice of suitable curriculum.

June, 2001 Contact Sue Heard, [petersue@senet.com.au](mailto:petersue@senet.com.au) for comments

1. To Develop an awareness of the educational needs of young people and to liaise with appropriate educational bodies and to promote access to equal educational opportunities,
2. To encourage educational systems to advocate on behalf of curriculum choices
  - a. Secondary Level, both Open Access and DETAFE Policy Levels
    - i. In partnership with and acting as a resource for central DETAFE Policy staff to develop educational material to for use by the schools and community
    - ii. Input through participation in parental management groups at Open Access College.
    - iii. Promote liaise between open Access and DETAFE policy units in the training of staff at the level of services provision in the area of hierarchical management superintendent levels , counseling services and to the Attendance Branch policies. to manage opportunities for children who have chronic disabilities.
  - b. Liaise with SABSA for equitable assessment processes for students who have a chronic recognized medical condition .
  - c. Encourage schools to promote CFS in curriculum areas such as health, domestic science, personal improvement courses (where strategies in managing absences from and return to school could be discussed) and sport .Again consultation and partnership in programme development is a desired objective.
  - d. Lobby for improved facilities for students in mainstream schooling – access to phones for lessons, a quiet (non-punitive) rest area etc.

## **II INFORMATION TO YOUTH AND PARENTS**

- a. The Society will assist youth and their families to negotiate the most appropriate curriculum choices, by providing information on changing DETAFE policy as it becomes available to us. The society will continue to promote the needs of our members towards equitable and flexible educational choices.
- b. The Society will encourage promotion of its activities and parental resource contact people, through publications such as the Open Access Magazine
- c. Appropriate information will also be provided via the Talking Point and SAYME Publications and websites: [www.sacfs.asn.au](http://www.sacfs.asn.au) & [www.sayme.org.au](http://www.sayme.org.au).

## **III CONSULTATION WITH MEMBERSHIP**

It is envisaged that the society will seek to involve as many of their members particularly the SAYME group and their parents, as well as country members in developing policies and programmes to meet the needs and interests of youth.

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A special task force of committed members may be formed to promote the interests of this group. Such a group would work closely with the Society Committee of Management, and with other relevant groups such as the Grants Committee, in obtaining funding to pursue objectives.

#### **IV ADDITIONAL OPPORTUNITIES FOR ACHIEVEMENT**

The society will also aim to create opportunities for youth to achieve success, in leadership and recreational pursuits outside of the formal education system. Involvement in the Duke of Edinburgh Award scheme is one such programme the society hopes to offer to its youth membership.

The society may well decide to implement an annual best practice award process to those schools (including country and private sector) which exhibit a responsive programme- or a pro-inclusion stance for children who straddle the fences of open access and mainstream schooling. The aim would be to recognize and reward endeavours by staff in schools who are willing to put some effort in meeting the special needs of children who have chronic fatigue.

#### **V TERTIARY SYSTEMS.**

Another component of an inclusion policy would be the readiness of tertiary institutions to offer a flexible entry programme for those students wishing to embark on a course of tertiary study. Some individual work has already been instigated with Flinders University and it is hoped that the society may be able to extend such possibilities in the future.

Next Review Date: Jun 2002