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# neuro – fibroma – tosis association of australia inc.

dedicated to support, research & public awareness since 1985  
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The Secretary  
Senate Employment, Workplace Relations  
and Education References Committee  
Suite S1.61. Parliament House  
CANBERRA ACT 2600

28 April 2002

Dear Sir/Madam

## **SUBMISSION TO THE SENATE EMPLOYMENT, WORKPLACE RELATIONS AND EDUCATION REFERENCES COMMITTEE**

### **INQUIRY INTO THE EDUCATION OF STUDENTS WITH DISABILITIES**

The Neurofibromatosis Association of Australia Inc (NFAA) welcomes the opportunity to present this submission on behalf of its members.

#### **What is Neurofibromatosis**

Neurofibromatosis (NF) is the name given to two distinct genetic disorders which primarily affect the nervous system. Neurofibromatosis type 1 (NF1), sometimes referred to as von Recklinghausen disease, is considered a common genetic disorder and occurs in 1 in 3,000 - 4,000 live births. Neurofibromatosis type 2 (NF2), referred to as bilateral acoustic neurofibromatosis, is less common but potentially more serious and occurs in 1 in 40,000 live births.

Both forms of NF are autosomal dominant genetic disorders. With both forms of NF, there is a 50% chance of each child of an affected parent receiving the gene for NF and thus developing NF1 or NF2, (depending on the type their parent has).

The NF1 gene is considered to have a high mutation rate. The implication of this is that 50% of people who develop NF1 will be the first in their family to develop it. The other 50% of people born with NF1 will have a parent with NF1. NF1 and NF2 are different disorders, they affect the body in different ways.

### ***Neurofibromatosis type 1 (NF1)***

NF1 is almost always apparent in infancy or early childhood. The main signs of NF1 are multiple café-au-lait spots or milk coffee birth marks, neurofibromas (benign tumours) and Lisch nodules on the iris. The café-au-lait spots and Lisch nodules do not have any functional effect on the individual. The neurofibromas may have a disfiguring effect if they are on the surface of the skin and in some individuals they may cause a degree of pain, if irritated.

NF1 is an extremely variable disorder. The severity of NF1 ranges from extremely mild whereby the above are the only manifestations (indeed the individual may never be diagnosed as having NF1), to more severe cases in which one or more complications may develop. The most common complication associated with NF1 in childhood is specific learning disabilities. Other complications include plexiform neurofibromas (larger lumps involving a group of nerves), macrocephaly (enlarged head), scoliosis (curvature of the spine), optic glioma (benign tumour of the optic nerve), pseudoarthrosis (resulting from fracture of limb bones, particularly tibia or fibula).

There is no way to predict who will have a mild case and who will develop serious complications. The majority of people with NF1 (probably 60%) have mild forms of the disorder. Another 20% have correctable problems and another 20% have serious and persistent problems.

### ***Neurofibromatosis type 2 (NF2)***

NF2 affects the central nervous system. NF2 is usually not apparent until later adolescence or adulthood. The main signs of NF2 are bilateral vestibular schwannomas (acoustic neuromas) which are benign tumours that grow on the nerves for hearing and balance and thus lead to hearing loss and co-ordination difficulties. Other signs include meningioma (tumours on the membranes covering the brain leading to pressure on the brain), spinal cord tumours leading to pain or weakness in limbs, cataracts on the lens of the eyes leading to problems with vision and neurofibromas (but different from those characteristic of NF1).

As with NF1, NF2 is also extremely variable in its manifestations.

Almost everyone with NF2 develops bilateral vestibular schwannomas. Persons with NF2 can develop brain tumours.

### **The Neurofibromatosis Association of Australia Inc (NFAA)**

The NFAA was founded in 1985, with the aim of bringing together individuals and families with NF for mutual support. Whilst the majority of its members reside in New South Wales, it has members located throughout Australia and overseas. The NFAA has a medical and scientific advisory board and has a close affiliation with the NF groups located in Victoria, South Australia and Western Australia and with similar NF groups located overseas.

The aims of the NFAA are to :

- Support members
- Increase public awareness of NF
- Increase awareness of NF amongst medical and health care professionals
- Alert education authorities to learning problems associated with NF
- Promote research into NF.

### **Educational issues arising from Neurofibromatosis**

There are a number of ways in which NF can result in students having special educational needs. These include the following:

- 1 As mentioned above, a complication of NF1 is that a person may have specific learning disabilities. This may mean that they under-perform in class tests.
- 2 Gross and/or fine motor co-ordination may be affected in students with NF1 or NF2. This can lead to problems with participation in sports or problems in writing or art and craft work.
- 3 Some children with NF have difficulty integrating in the school environment because of the variety of symptoms of their NF. This can result in social isolation because of an inability to keep up in class or an inability to participate in the full range of school activities, such as sport. Physical differences from other children arising from visible tumour growth and bone deformities can make children feel self-conscious. This can have adverse consequences to the social development of the child.
- 4 Some children will have extensive periods of hospitalisation and as a result may require intensive catch up assistance on their return to school.

### **Neurofibromatosis and Learning Disabilities**

As stated previously, the most common complication of NF1 is specific learning disabilities. Estimates of the incidence of learning disabilities in children with NF1 vary from 30-60% depending on the study. A specific learning disability usually means there is a discrepancy between the child's assessed ability (perhaps IQ score) and their performance (school test results). When children with NF1 perform at levels lower than expected they are often accused of being lazy or inattentive and therefore do not get the help they need. Most children with NF1 have an IQ within the normal range but tend to perform at levels lower than their siblings.

Some children with NF1 are also diagnosed with Attention Deficit Disorder (ADD) or they may be impulsive and disruptive in class. They may also have problems with co-ordination which limits them in participating in sport. Problems in fine motor coordination makes writing difficult and they may have problems in producing neat and tidy school work. The combination of lower performance at school and behavioural problems means that these children may have low self-esteem. Many of them have difficulties in social interaction with their peers.

Whilst research into the nature of learning disabilities with NF is ongoing, information available from the National Neurofibromatosis Foundation, Inc in the United States suggests that both language and non-verbal dysfunction is present with NF1. The exact form of the learning disability and the degree of severity will vary with the child. Some experience difficulty with visual and spatial skills, some with speech and language, some with reading and maths and some are affected by a combination of these. In addition some have difficulty with focussing attention.<sup>1</sup>

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<sup>1</sup> "The Child with Neurofibromatosis 1" Bruce R Korf - National Neurofibromatosis Foundation Inc.

The following specific language and non-verbal dysfunctions are listed by the National Neurofibromatosis Foundation, Inc as being associated with NF1<sup>2</sup>:

#### *Language dysfunctions*

- 1 *Weak attention to verbal information.* This can involve poor listening skills and distractibility in school or other group situations where much talking occurs. There can also be difficulty with listening for long periods of time.
- 2 *Weak verbal memory.* This can involve poor memory for rules of language and word sequences.
- 3 *Weak understanding of word meanings.* This can involve limited vocabulary, poor reading and trouble with word problems in maths.
- 4 *Poor verbal problem solving skills.*
- 5 *Poor understanding of language in social situations.* This can entail difficulty with interpreting a person's meaning or intentions in social situations.
- 6 *Difficulty in distinguishing sounds.* This can involve problems with sound symbol association in reading and phonics.
- 7 *Limited vocabulary and slow word retrieval.*
- 8 *Disorganisation in communication.* This can occur with both spoken and written language used for describing events and telling stories.

#### *Non-verbal dysfunctions*

- 1 *Weak visual spatial skills.* This results in difficulty in interpreting position or direction and in orienting oneself to his or her surroundings.
- 2 *Weak simultaneous processing of visual-spatial information.* This involves difficulty in interpreting, organising or working precisely with spatial information such as maps, diagrams, graphs and complex charts, music and maths. There can also be poor spatial planning and visual organisation for writing, drawing and organising material spatially on a page.
- 3 *Weak visual motor integration.* This involves slow, uncoordinated and imprecise copying, writing of numbers and words or drawing. It can also result in poor mechanical and construction skills for arts and crafts and poor athletic skills for catching, hitting or kicking a ball.

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<sup>2</sup> "Achieving in spite of... A Booklet on Learning Disabilities" C V Dilts and P Bellermann National Neurofibromatosis Foundation Inc.

## **Teachers Information Kit**

Having recognised the educational problems associated with NF, the NFAA has been working on the production of a Teachers Information Kit. The objective in producing the Kit is to provide teachers of children with NF with information about the learning disabilities associated with the condition, so that they can be aware of the potential problems facing these children, identify the nature of specific problems that manifest themselves and, with relevant expert help, develop strategies to overcome these problems.

The NFAA is hoping, in preparing its Kit, to use information being prepared by the Children's Hospital Education Research Institute (CHERI) at the Children's Hospital at Westmead, as important research work has been carried out there, leading to development of practical strategies for addressing the needs of NF children with learning disabilities in the classroom.

In preparing for the production of the Kit, we carried out a survey of members, with a view to ensuring that the Kit would be relevant to members. One of the objectives of the survey has also been to include in the Kit the experiences of people with NF, and of their parents, on the basis that these experiences could prove useful to others in similar circumstances.

### **Experience of our members**

The NFAA has obtained information about the impact of learning disabilities and the other educational difficulties associated with NF, from a number of sources over the past 2 years. These have included:

- 1 The member survey carried out for the purposes of the teachers' kit referred to above.
- 2 A further recent survey carried out for the purposes of preparing a submission for the current enquiry by the Australian Law Reform Commission and the Australian Health Ethics Committee into the protection of human genetic information.
- 3 Information provided to our support worker by members seeking support and assistance.
- 4 Material submitted by members to our newsletter, "Neuro-fibro-matosis News".

We have drawn from these sources to provide the following information, comprising both specific experiences about learning and educational difficulties of our members and their children and some general observations drawn from common experiences of a number of members.

### ***Specific Experiences***

- 1 One member, who has a daughter with NF1 and who had lived in a rural area, relates how she had experienced discrimination in connection with her daughter's education. The daughter had been placed on a community based pre-school waiting list as a baby. At that time the parents had no knowledge of the child's NF. When the child was three years of age the director of the pre-school informed the parents that because the child had special needs and because the parents had not notified of this at the time of enrolment, the child could not be given a place. The reason given was that the pre-school had already filled its quota of special needs children.

This same family had older children at a non-governmental school in the same town. That school expressed concern that the child with NF may not fit into the mainstream and that it would be wise for the parents to seek alternatives, despite the parents' protestations that each child with NF is unique and that it could well be that their child would have few complications. As advised by

the school, the concern was that the school could not cope with possible physical restrictions nor provide support for a child with learning difficulties.

This case illustrates the fact that a child may have no learning disabilities but may have educational restrictions imposed on them simply because a school is aware of the diagnosis of NF. A quandary for many parents of young children with NF, who does not present with any obvious learning disability problem at a young age, is the concern that by disclosing to the child's school the fact that the child has NF and therefore may have such a disability, will in some respects be self fulfilling. The concern is that the child's education will suffer because of the disclosure and the assumptions that may then be made about the child's abilities, irrespective of whether any actual learning disability is found to exist.

- 2 Another member advised that her son had two main problems with NF, debilitating migraine headaches and learning disabilities.

She indicated that the most difficult problem was the learning disabilities. Her son had a visual perception problem, which made learning to read and write harder than normal. Tests indicated that her son had significant problems with saccadic eye movements or "jump" movements, which are needed for tracking. The mother was advised that poor eye movement control can cause loss of place and the omission of small words when reading. This made copying from the board difficult, or in her son's case impossible. Testing showed that her son could not tell if letters or numbers were reversed and that he didn't see whole words but only letters, and then not always in the right order.

This parent reported that it was not easy to get help at school for her son. It was very difficult to convince some of the teachers that a child with a high IQ could have such learning difficulties. She was concerned that a child can appear to be lazy when they can get 100% on a maths test or could stand up in class and speak on any subject, but not be able to learn a few spelling words in a week. The parent stated that her child was very clever and had managed to hide a lot of his problems from both his classmates and his teachers.

The parent indicated that she had to act as her son's advocate at school. She was able to persuade the teachers to give her son written copies or work instead of him having to copy from the board or from a book. She advised that the parents also engaged a tutor to come to their home once a week to help with the son's reading. With the parents knowledge of the son's disability, she was able to explain to the tutor the boy's problem and the tutor was able to tailor a program for him. The result was a great improvement over a three year period.

- 3 One member reported that she fell into the category of "undiagnosed" disability until her early adult years when she was finally able to arrange some testing for herself. She had a problem with physical coordination, writing in particular, and extremely poor spelling. Her reading, however, was always above average.

Her main difficulties occurred in late high school years when there were increased demands for writing. This meant she failed her HSC when first attempted, because she couldn't write well enough to take adequate notes in class or complete an exam. She was constantly told she was very good, and that the problem had to be because she was 'being lazy' or 'sloppy' or 'not trying'.

The member reports having in fact shed many tears in frustration and over the effort of trying. No one had suggested to her that the vast discrepancy between her verbal skills, determined attitude and the resultant output needed further investigation. Eventually she found a specialist organization who gave her a catch all diagnosis of "developmental learning disability" but did not address her physical problems.

This member subsequently completed her HSC and then qualified as a radiographer. She has since completed an undergraduate degree with support from the disability unit at her university. She had help in the form of a note taker in lectures and scribes for exams. She averaged at a distinction level for her undergraduate degree. She has been very successful with her studies with this support. However it was a very long, frustrating and painful search for help. This member is now enrolled in post graduate studies at a different university.

This member reported that the invention of the microprocessor has been very important to her. She finds her electronic dictionary to be of great assistance. She feels that it has improved her spelling enormously. It gives her confidence to use the word that she wants to use, rather than a word she can spell. Paper dictionaries are of little assistance to her as it is necessary that you have a close idea of the spelling. With the electronic dictionary, she is able to input the word phonetically and the dictionary will suggest spellings.

- 4 The father of a nine-year-old girl with NF advised of the cost the family had incurred in obtaining special tutoring and therapy outside the child's school.

The girl attends a private school. The parents recognised that their daughter was having difficulty with reading in kindergarten, although it wasn't until late in year 2 that it became obvious to them that the child was also not developing in the areas of handwriting, spelling and maths. Testing by a private occupational therapist confirmed that she was well below chronological age on a number of tests and that these would impact particularly on handwriting and reading and affect her ability to carry out a majority of school tasks.

The girl attended a private programme during 2001 which focussed on reading. This entailed two one hour lessons per week after school, at a cost of \$100 per week. This programme closed at the end of 2001 and the parents had to then organise alternative assistance. This included a former state school special needs teacher, who had set up a private special needs service when the reading program she taught at the local public school was closed down. She takes the child for one hour per week and focuses on reading and writing.

The child also attends a one hour session each week with a maths specialist. In addition the child has had some therapy sessions with a speech pathologist who has been focussing on her reading and spelling. The cost for each of these services is approximately \$90 per hour. Unlike the other two amounts, only the cost of the speech pathologist is recoverable (in part) from the parent's private health insurance.

- 5 The mother of a seven-year-old boy with NF1 advised of her experience when filling in the form to receive New South Wales state school education funding for children with disabilities and of the effectiveness of the support ultimately provided. This boy has no specific learning disability but has had regular periods of hospitalisation in connection with NF related complications and hence has had a number of absences from school.

The parents and school applied for funding when the boy started school, to allow for the provision of a teacher's aide in the classroom. This assistance was provided in class for one term, while the boy recovered from surgery. Whilst the aide took some of the load off the teacher, the mother felt that there was very little interaction between the aide and her son and she felt that there was little real direct assistance provided.

The mother felt that children with NF do not fit the requirements described in the funding application form. There is no category for children with NF. Children with NF1 often have a range of smaller problems which the mother feels do not seem to add up to much on the

application form. Hence, while her application was successful in achieving funding for the teacher's aide due to her son's physical needs, she considers that NF children generally would be unlikely to get funding.

When filling in the form for funding, the mother's view was that it appeared that only those children whose parents and teaching staff (eg the school councillor) are fully experienced in filling in the form, and motivated to obtain the funding, are likely to achieve the funding. She thought that there was a problem in the format of the form, making this type of funding hard to acquire.

### *General Observations*

The survey material obtained in connection with the teachers kit draw out a number of common themes. Some of these themes are also apparent from the information obtained from other sources. These themes include the following:

1 *Importance of teachers' understanding the nature of the disability*

Although members do report that teachers often have an understanding attitude to their or their child's learning difficulties, a common concern expressed by many is that the child with an NF related learning disability is considered by some teachers to be lazy and lacking concentration. Members consider it to be particularly important that teachers are adequately trained to understand the nature of learning disabilities and to be able to identify them.

2 *Need for early recognition of learning disabilities*

Early recognition that a learning disability exists will mean earlier and hopefully more successful intervention. Intervention should be conducted within a regular school setting. Children need to be taught strategies to deal with the problems they experience.

3 *Isolation and poor development of social skills*

It is important that schools recognise their role in the social development of children with disabilities. Many children with NF1 have problems relating to their peer group. They may prefer to play with children who are either younger or older than them. Many of our member responses indicate that children with NF feel isolated. This isolation may be due to a lack of social skills or else physical problems which make it difficult for them to participate in sporting activities.

4 *Organisation and structuring of tasks*

Children with NF1 often experience difficulties in organising and structuring learning tasks. This will impact on the child's ability to carry out many school activities, particularly in the later school years when the child is under less supervision. Children with NF1 can learn and retain information better when it is presented in a structured way. Teachers need the resources to help children in this way.

5 *Need for specialised physical education services*

In addition to the issues of social isolation arising from an inability to keep up in sporting activities, the fact that a child with NF cannot fully participate in physical education and sport can mean that they miss out in the gross motor and health benefits associated with this.



**Observations relevant to the issues being considered by the Inquiry**

1 It is important that teachers of children with NF be aware of the potential for learning disabilities associated with this condition. This will allow them to pick up on a problem at the earliest possible stage, so that adequate assessment can be carried out and intervention programmes put in place as early as possible.

Our members have expressed concerns which suggest that many teachers do not have an adequate understanding of learning disabilities. This could be redressed by adequate ongoing professional development in this area.

2 Early assessment and intervention is important. This means that there needs to be assessment and intervention programmes available to children who have, or are suspected of having, learning disabilities. Further, both parents and teachers who are aware of a problem need to have access to information about possible options.

The Teachers Kit being prepared by our Association aims to assist in filling a gap in that regard. We would hope that the various Education Departments will be supportive of this type of initiative by groups such as ours.

3 In many cases children with NF related learning disabilities will require intensive assistance. One on one assistance may be essential. Such assistance comes at considerable cost. This will often not be available in the regular school environment, even in those cases where special needs teachers are available.

If the state is not prepared to support these children then parents should be encouraged to seek relevant private assistance, by appropriate tax relief. This can be seen as a trade off against the likely cost to society in future of having individuals employed in areas below their abilities and paying less tax than if they were in employment commensurate with their ability.

4 The system of obtaining special educational assistance at school needs to be reviewed. As noted above, the application process can itself be difficult, particularly with cases like NF which are not covered by the standard application forms.

Further, the result of such an application will often be the employment of a teacher's aide. The aide will not necessarily have any training in the special needs of the disabled child. Whilst the teacher may be assisted by having an aide in the classroom, the effectiveness of such an aide to the disabled child's needs is questionable.

5 Schools should be encouraged to focus on the social and physical development of disabled children, such as those with NF. Many of our members are concerned about the social isolation their children experience whether it be through poor social skills or lack of participation in sports due to poor coordination.

There is a need to develop better programmes that will integrate children with conditions such as NF into the full range of school activities.

We thank you again for the opportunity to present the views of the NFAA. Should you require any clarification, please feel free to contact us at the above address.

Yours sincerely

A handwritten signature in black ink, appearing to read 'R. Pynor', with a stylized flourish at the end.

Rosemary Pynor  
President