'Anonymous' – an organization for families of children with undiagnosed brain diseases

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As a consultant child neurologist with opportunities over many years to travel widely throughout Sweden, I have time and again seen severely brain impaired children, without any reasonable explanation for their condition and with a disturbing lack of precise diagnosis, despite vigorous investigations. Not even a name for the disastrous condition could be provided for the frustrated parents. Whilst understanding that an effective treatment was impossible to find, these families repeatedly asked for new consultations in the hope of at least a precise diagnosis and a label. Indeed, it is a hard burden for any family to have a child with a hopelessly progressive brain disorder, and ignorance as to the cause makes it even worse. There are no experiences to learn from, no straws to clutch for help, no hope for meaningful treatment, no special interest group to join.

Encouraged by the Swedish Social Council in their 1994-97 campaign for 'Small and less well known handicap groups', I took the initiative to start a family network group for support and information to families with situations as described. 'Anonymous' was rapidly established through this official support and with financial starting grants. From being a pioneering project in 1994, the activity has since 1997 become established as an independent special parents' interest organization.

The project immediately created wide interest and became an instant success among families with these problems. Their relief to meet other parents in the same situation was great. The medical information and lectures by me and my colleagues certainly were appreciated, but no doubt to get to know each other and to share years of experiences and feelings of other families, was the main advantage. Endless talking and talking through the night took place at these meetings.

What has the reaction of the medical profession been? Largely, a very positive one! Those mainly involved have been the neuropediatricians within the habilitation teams at county and university levels. A prerequisite for joining the Swedish project 'Anonymous' has been that the responsible medical project leader (B Hagberg) gets written consent from the parents to contact their doctor for actual medical information. With the close network between Swedish neuropediatricians, that requirement has not posed any problem. On the contrary, an interesting and increasingly productive discussion over differential diagnoses has often developed.

Among the progressive brain disorders, an impressive and growing list of several hundred different conditions has already been identified worldwide, but there are certainly a substantial number of such diseases still unclassified as to type and background. Altogether, progressive brain disorders during childhood in Sweden have a prevalence of about 0.5 per 1000. Thus such conditions are of a magnitude similar to that of well known groups such as neural tube defects, infantile hydrocephalus (simple type) and hemiplegic forms of cerebral palsy.

Keywords: Leucodystrophy. Degenerative brain disorder. Encephalopathy.
Initially the project concentrated particularly on addressing families with a child affected with progressive unknown types of brain disorder. In addition to this original special target group, it soon became apparent that there was an even larger group of children with different, unexplained, non-progressive encephalopathies, where a diagnosis had been impossible to reach in spite of vigorous efforts to reveal type and origin. Many such families also ended up in the same situation of despair and disappointment after years of searching for a diagnosis. Surprisingly it soon appeared that also in this group there was a substantial incidence of families with more than one affected child.

As of September 1998 the Swedish ‘Anonymous’ children numbered 135 within this interest organization, comprising 120 unrelated families. Of the children so far involved, 95% fall into one of the two principal groups of clinical categories: unknown progressive encephalopathies (one-third of cases) and non-progressive encephalopathies, where defined syndromes and other conditions have been excluded (two-thirds of cases). A small third group comprises children with sequelae after unknown inflammatory (dysimmune?) and related brain processes. Interesting new clinical experiences have been learned from this collected group of diagnostically ‘Anonymous’ children. Some novel and apparently unknown types of ‘white matter’ (dysmyelination) conditions have been seen, sometimes with variation in severity between siblings.²

In conclusion I would emphasize that for these ‘Anonymous’ parents, the most important relief and support has been achieved by meeting each other and getting to know families in the same situation, for discussion and sharing problems and particularly to experience that they are not alone and no longer isolated. This in itself is therapeutic.

References
