

# History of the NSPKU

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The National Society for Phenylketonuria (United Kingdom) Limited - or NSPKU for short - exists to support people with Phenylketonuria (PKU), their families and carers. It is the oldest PKU support organisation in the world.

The Society was founded in 1973 by Brian and Sylvia Smith of Runcorn. They arranged for an announcement, over BBC Radio 2 on Jimmy Young's programme, that if anyone was interested in forming a Society for Phenylketonuria they should come along to The Temporary Community Centre, 40 Cunliffe Close, Palace Fields, Runcorn on Sunday 25th November 1973 or contact Mr. Smith direct. They also wrote to families and dietitians whom they knew or had addresses for. A small number of families attended the meeting and set up a steering committee which got the Society under way. The first chairman was Brian Smith. They held their first General Meeting in Blackpool in April 1974. This was attended by a few families.

Since then the Society has continued to grow. The Annual Conference and Holiday weekend takes place in early March and is now attended by about 100 families as well as many medical professionals and food companies. The NSPKU and local PKU Support Groups now organise many different events during the year. These take place around the UK to enable as many people as possible to attend.

From the first meeting the Society set out to gain charitable status and lay down a set of rules by producing a 'Memorandum of Association' which was finalised in August 1975. This enabled the Society to become a limited company in 1976. Charitable status came some time later.

In the early years, the Society was largely for families to share information. It was also recognised that we needed the support of medical professionals. A Medical Advisory Panel (MAP) was formed in 1975 and now consists of clinicians, dietitians, a psychologist, 4 Council of Management members and the Society dietitian. It meets twice a year and acts as an interface between the Society and the medical profession. Many MAP members write or offer editorial assistance in producing Society publications. In the formative years, Dorothy Francis - dietitian at Great Ormond Street Hospital in London - worked very hard for the Society and produced our first food exchange lists until we employed our own dietitian in March 1983. The food lists produced by the NSPKU are now an essential part of the information used by dietitians across the UK for the treatment of their PKU patients. The government now recognises this and is currently providing some funding for this service.

To provide people with information about PKU, the NSPKU has developed - and is continuing to extend - an extensive range of literature. Each publication is targeted for a specific need, eg. for people with PKU, parents of PKUs, members of the medical profession and other professionals such as teachers and employers.

As funds become available, the Society has funded the analysis of foods and provision of equipment for PKU genetic research.

The NSPKU has continued to grow. From the early days of a few families, the membership has grown to over 900 families or individuals on the NSPKU mailing list and more than 170 medical professionals who subscribe to our literature.

The Society became a founding member of the European Society for Phenylketonuria and Allied Disorders (ESPKU) on 4th October 1987. The ESPKU co-ordinates the campaign for an improved quality of life for all PKUs in Europe.

In July 1996, the NSPKU established a presence on the internet. The NSPKU site now has over 40 pages. There are relatively few graphics on the site. This allows faster download times.

The NSPKU recently celebrated its Silver Jubilee. There is still much for the Society to do, particularly in the area of adults with PKU. This is a rapidly growing area for the NSPKU as more and more PKU teenagers and adults are choosing to stay on a reduced phenylalanine diet for life. There is also the continuing drive, with food manufacturers, to improve and expand the low-protein products available to people with PKU. A major project on which the NSPKU is currently engaged is the production of a 'PKU Management' handbook. This is being produced with the assistance of many leading UK medical experts on PKU and is designed to set out the standard for PKU treatment in the UK.