National Society for Phenylketonuria

SUPPORT GROUP INFORMATION GUIDE

SETTING UP A SUPPORT GROUP FOR THE NATIONAL SOCIETY FOR PHENYLKETONURIA (NSPKU)

INTRODUCTION

The purpose of this information pack is to provide guidance and assistance to new and existing NSPKU Support Groups. It contains helpful tips on how to set up a support group and many suggestions on the role and activities that the Group can play. The guidance is flexible to allow Groups to evolve to meet the needs of those participating within an overall framework.

Support groups play a vital role in the “PKU family” with individuals and families coming together to support each other in many ways, as everyone gets on with their daily lives.

The NSPKU hopes this new guide will be helpful to existing and new families who want to establish a local support group. Further helpful information and contact details for support groups can be found on the NSPKU website www.nspku.org.

This guide provides a whole host of ideas, however, it is important to remember that in some circumstances a support group can be an informal affair, involving the occasional get together. For example you may want to make contact with a child of a similar age to yours and your dietitian may be able to help here. You may meet up for a coffee and initial chat and develop ongoing contact. This may develop with one or two more people coming together informally to have an afternoon together. These friendships will probably develop and be of real benefit to the children and families. Christmas parties may be organised or a trip to the bowling alley or similar. The network may stay informal or may grow into a more structured support group. The most important thing to remember is to do what is right for you.

Please take the ideas from this guide that will best work for you and the PKU families around you, whether it be a formal or informal group.

Don’t forget that what works is what matters.

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The NSPKU

The National Society for Phenylketonuria (NSPKU) was founded in 1973 by parents and acts as a support to families and adults. It has a dedicated team of medical advisors experienced in its treatment. The NSPKU has a Council of Management (COM) comprised of people with PKU, parents of people with PKU, Dietitian and administrator.

The COM is responsible for the operation of the charity and produces a range of information including:

- Quarterly magazine called ***News and Views***;
- Dietary books on PKU produced by our Dietitian;
- News on research into PKU;
- Recipes;
- Experiences of people with PKU;
- Details of conferences;
- Social events at conferences;
- Outward bound weekends; and,
- Study days.

The NSPKU Council of Management:

- Meets several times throughout the year to run the Society;
- Meets experienced medical professionals to discuss research and developments (Medical Advisory Panel - MAP); and,
- Plans study days and an annual conference.

The outcomes from these events are reported in ***News and views***.

There are a number of Support Groups throughout the country run by parents and details of existing groups are shown on the inside front cover of News and Views.

Aims and objectives of the support group

The aims and objectives of the Support Group is to:

Put people in contact with each other.
Provide support to families in the area covered through local contacts.
Provide friendship to people involved in the dietary management of PKU.
Promote a healthy relationship between parents and their children.
Give moral and emotional support.
Build self esteem – everyone needs to feel valued to give value.
Give practical help wherever possible.
Provide guidance on the information available.
Share experiences – the good and the not so good.
Hold events where everyone can come together
Provide a networking opportunity for families.
Help improve the quality of life by individuals / families supporting each other.

Marketing – Letting people know

You will need to think about how to reach individuals and families in your area. Some will be members of the NSPKU and others will not. Getting answers to some of these questions will help you get started.

- Who are they?
- What will attract their attention?
- How can I contact them?
- What do I tell them?

Information gathering

Who is the NSPKU support Group co-ordinator? John Skidmore supportgroups@nspku.org How can I find out who are members of the NSPKU in my area? Lucy Welch will help by sending information to members in the area info@nspku.org in accordance with our data protection responsibilities.

How can I contact my area hospital dieticians to promote the Group? By getting the support of the dietitian in the regional hospital to send out the information to dietitian colleagues in the area.
What activities do other Support Groups get involved in? Contact the NSPKU support group co-ordinator or alternatively another Support Group co-ordinator. Details can be found on the NSPKW website www.nspku.org or on the inside page of the NSPKU publication - *News and Views.*

Places to advertise

Make use of the various opportunities to promote the Support Group for example:
Local Hospital dietitian(s)
Advertising in News and Views
NSPKU website
Display posters in the local Hospitals
Through local media
Word of mouth
Written invitations

Welcome and introductions

People attending the group may be anxious about being there. It is therefore very important to welcome individuals as they arrive, introduce them to others and offer refreshments. It may be wise to check they have no specific needs as everyone is different and that is OK. Stickers and felt tips to personalise a name label gives people something to do and provides a talking point as well as everyone being able to know each others name. It is important to allow time during the first session to introduce and welcome everyone, both individually and as a group, without intimidating them.

When everyone has arrived make sure you tell the group where the toilet, fire exit and refreshments area is. It may be helpful to agree break times and to give an idea of what the session will include. Remember - this may be a difficult situation for some individuals / families and they will need you to be supportive.

A good starting point may be to take feedback on what parents want to get out of the group and to list their expectations on say a flip chart. This is also useful to refer to when you evaluate afterwards.

Give parents the opportunity to ask questions and to discuss any concerns. This will give you the opportunity to reassure them. In some cases you can put families in contact with each other for example where the children are about the same age.

It is also important to stress that::

- No-one is perfect and knows everything about PKU – there isn't just one "right" way – everyone is different
- remind them of all the skills they have already and re-assure them
- parents should only share what they feel comfortable sharing

Running the first meeting

Every successful meeting has someone who chairs, or facilitates, the gathering. It is preferable that those who are attending elect the chairperson / facilitator / convenor, or whatever the name of that person may be. However because you were the one who "set the ball rolling", then it is you who probably will be given the job, perhaps for this initial meeting only. However you may have decided to get someone else to chair the first meeting for example your dietitian. You also need to have in mind whether you need:

- Someone who keeps a note of the major points discussed and suggestions made (the Secretary)
- A person who looks after any money gathered or raised through individual activities, even if it is only for the tea, coffee and biscuits (the Treasurer)

The purpose of the initial meeting will be to establish if a number of you want to go ahead and start a Support Group in your area. It will give everyone who comes a chance to share ideas on how to get going.

It may be helpful to have a broad idea beforehand of what should be discussed and you could put together a simple agenda to help keep the meeting on course. The kinds of things likely to be discussed are:

- What you might want to do as a group?
- Practicalities of establishing a group?
- How do other groups manage?
- What do they do?
- How can the NSPKU help?

In any event essentially what the person who is in the chair needs to do is:

- to satisfy themselves that the venue is a "safe" one for those likely to attend
- Make everyone who comes feel welcome
- Set simple "ground rules"
- Do not let the same people talk all the time, give everyone a chance to have their say if they want to
- In the event of a dispute act as the arbitrator
- Sum up from the proceedings
- Get agreement on the next meeting and, in a general sense, state what will take place
- Thank everyone for attending

Remember to allow time for people the opportunity to have an informal discussion after the meeting, as some people may find the experience / issues discussed somewhat difficult. They may not have felt confident to ask questions in front of others and they may need to be reassured.

A "good" meeting is one that as many people as possible enjoyed. So, the best of luck to you.

Afterwards

Thought needs to be given to the timetabling of meetings so they fit in with school, work and family life.

If by the end of the meeting you decide to go ahead, you probably will also have identified the steps to be taken over the following weeks/months.

If you decide to seek further assistance from us we can register your group as a NSPKU Support Group, and then we will put enquirers from the area you cover in touch with your group and begin to network your group with other resources of help and support in your locality. The NSPKU and not the Charity Commission would register the group. However, if a group has substantial income and expenditure it is advisable for the group to be registered in their own right as a charity direct with the Charity Commission.

Groups can be different

Different people have different needs and it is important to acknowledge the culture and context of the group. There may be needs and issues specific to individual groups and it is important that you negotiate within the group about how these are addressed. Particular group needs may have been identified prior to the first meeting. However, they may not become fully apparent until you start discussing hopes and fears and ground rules.

Individual needs should also be identified and heard. It is important to have realistic expectations of individuals and parents and to encourage them to progress at their own pace, offering guidance and encouragement when necessary.

There are lots of different styles of learning about PKU and different people learn in different ways. Some people learn through discussion, some through reading, some through participation in activities. Trying new ways and making mistakes are part of the process, but if people are worried about not getting it “right” they may give up. It is important to remind parents of all the successful things they already do and of all the skills they already have. Much of the group’s activities are likely to centre around discussion. But every group is different and this guidance framework therefore caters for all needs.

Examples of the type of things Groups may get involved with include:

- Cookery demonstrations including “hands on” workshops
- Presentations from the health professionals on particular topics - blood taking, how do we analyse the blood, the role of paediatricains and Dietitians, research updates,
- Christmas party - santa, bouncy castle, children's entertainer etc.
- Creche / children's entertainer may be an option if there is a meeting with presentations for teenagers / adults.
- Summer "garden" party
- Charity fundraising event.
- Picnic day
- Meeting just to catch up over some refreshments.

This list is by no way exhaustive.
NB: If a group were to offer a crèche with large numbers of children, then consideration needs to be given to child protection issues.

Ground Rules

Ask those attending what would help them feel safe in the group. Write their ideas onto a flip chart and this will give the basis for many of the ground rules. Remember that this may be the first time they have been asked to do this and you may need to prompt and encourage.

Some ideas to include are:

- accepting differences
- no pressure to speak
- listening
- confidentiality
- it is OK to make mistakes
- it is OK to make silly suggestions (frequently they are not)
- being able to add new ground rules at a later session

Remember that, for some, this will be the first time they have been in a group situation since leaving school.

Additional support

The NSPKU Council of Management will provide as much support as possible to enable the group to function effectively. The NSPKU have appointed a support group co-ordinator to provide additional support. It would be really helpful if the Support Group made use of the quarterly publication – *News and Views* and / or the NSPKU website, to provide regular feedback on the activities of the group and to publicise future events.

Venue

The venue needs to be accessible, preferably on a bus route and with good parking. Please bear in mind the access needs of people with disabilities. People attending should be offered a welcoming environment which all helps to get off to a good start.

Wherever the venue is, it should be prepared carefully before everyone arrives. The room should be comfortably warm with chairs arranged appropriately. You may wish to provide refreshments for PKU and non PKU foods.

It may be an idea to have some materials available, for example (flip charts, paper, pencils, toys, games, music, TV / video , entertainer, bouncy castle etc).

Resources

It is important to be aware of the cultural diversity within the group and make this a consideration when planning.

Allow time at the end of each session for parents to say what they did and didn't find useful.

Allow time at the beginning of each session for parents to say how things have gone since the last meeting. You could ask such questions as: What worked? What was a struggle? What else could you try? What would help? How did other members of the family respond? How was it at school? How did the holiday go?

The Group can decide to raise funds for its own use by organising fundraising events or through charity raffles or by individuals participating in events to raise funds for the Group. It is advisable to set up a bank account for the Group controlled through say the Treasurer and Chairperson of the Group.

It is advisable for the group to put in place insurance so events are covered. Insurance has to be arranged by each individual Support Group, the NSPKU does not provide cover.

We recommend each Group uses an ordinary postal address and not a PO Box.

Finances

If you are to handle money in relation to your support group you will need to open a bank account. It is worth shopping around as banking rates and charges are variable. You will probably need a business account. There are some charity accounts available but you will probably have to be registered as a charity to benefit from these. In any bank account it would be advisable to have a requirement for two signatures for any financial transactions.

It would also be advisable to elect someone to be responsible for the finances of your group (a treasurer). This person would be responsible for all monies coming in and out of the group as well as issues such as investing, accounting, expenses, budgeting.
If your group has, in any year, a total income, which exceeds £1000 you, must register your group as a charity with the Charities Commission. You can find more information about this organisation and the relevant requirements at www.charitiescomission.gov or via their call centre on 0870 333 0123.

If you would like further information, advice or guidance on financial matters please contact the Society Treasurer treasurer@nspku.org

Insurance

In these days of mass litigation it is always advisable to have some sort of insurance in place for organised activities and events. A public liability insurance will protect you in these instances. You may also need an employers liability insurance to cover any volunteers who work on your behalf in any capacity. If you sell any products you may also need some sort of trade risk insurance. Once again it is best to shop around and insurance companies will be able to advise you on the insurance your group will need to suit it's needs.

Evaluation

It may be an idea to leave enough time during the meeting for group members to review and evaluate the event. You might ask them:

- What did you like about the day?
- What are you leaving behind?
- What are you taking with you?

Remember to thank everyone for taking part.

Evaluating the Support Group is important. It enables you to measure the impact and benefits for individuals and families and whether the objectives of the group have been achieved. It can also be valuable to collect quotes and comments from group members (for example, one parent said: “I thought I was the only one in this situation.”)

If you do not have evaluation forms please contact the NSPKU support group co-ordinator who will provide you with a standard from.

There is also the opportunity to display promotional information and sell NSPKU merchandise. This can be used to help the group raise some funds! Please contact Lucy Welch for details.

We hope that you enjoy running your support group for people with PKU, their families and those that support them. I am sure you too will get real benefit from organising the group as much as those attending.

Remember the type of Support Group and what takes place is down to those in the Group and this guide is intended to provoke thought and debate to help shape the group.

Good Luck!

Contact details

The National Society for Phenylketonuria can be contacted by post, helpline number or via our website.

Email: info@nspku.org

Website www.nspku.org

Telephone Helpline: 0845 603 9136
Fax: 0845 004 8341

Address: NSPKU,
P.O. Box 26642
London N14 4ZF

The management of PKU is a great medical success story and this guide is intended to help further improve the quality of lives for people with PKU and their families.