

The logo consists of the letters 'NSPKU' in a bold, sans-serif font. 'NS' is black and 'PKU' is white, all contained within a green speech bubble shape with a small tail pointing downwards.

**NSPKU**

A green ribbon banner with a slight 3D effect, featuring the text '51<sup>st</sup> CONFERENCE 2024' in white, bold, sans-serif capital letters.

**51<sup>st</sup> CONFERENCE 2024**

**17th - 19th May**  
**Chesford Grange**

Our goal is to support individuals and families living with phenylketonuria (PKU).

We engage in education and research to support everyone affected by this condition.

We campaign and advocate for better standards of treatment to enable people with PKU to live the best possible life.

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In association with



# Welcome!

On behalf of the NSPKU Board, I'm delighted to welcome you all to our 51st Annual Conference at Chesford Grange Hotel in Kenilworth. Like any organisation, the NSPKU wants to constantly evolve and remain relevant to our membership, and the best way to do that is to speak to you! The conference is a great opportunity to get involved, make new friends, meet up with old friends and hear more about new treatments, research and all things PKU!

As ever, this years' programme will be varied with something of interest for all. There will be opportunities to enjoy Chesford Grange's nature trail whilst engaging in a walking meeting; there will also be the usual mix of speakers, workshops, updates and discussion panels on a wide range of issues and topics that affect our community.

As usual, we will have a fully supervised crèche onsite, a children's pyjama party, plus activities for our older kids and a dedicated chill-out room (Young Adult Games Room). In addition, there will be plenty of time for socialising, with dinners on both Friday and Saturday evening, complete with entertainment.

The conference is always a mammoth organisational task, and I'd like to extend a huge thanks to our dedicated staff and volunteers and to our hosts for the hard work that goes into running these events, in addition to our sponsors and partners, we really couldn't do it without them, so a huge thank you to all involved.

All that remains is to enjoy the conference, and please do seek out and speak to us all at the NSPKU.



Andrew Thompson  
Chair of NSPKU



## Friday 17th May

**3-6pm**

Registration

**5pm**

WALK AND TALK Number 1  
Chesford Grange Nature Trail  
Meet by NSPKU desk

**6:30pm**

Welcome Drinks Reception

**7pm**

Welcome Dinner  
Sponsored by Promin

Drinks and Dinner will take place in  
Kenilworth 1 & 2

## 6

Topic	Speaker	Time	Location
WALK AND TALK number 2	Chesford Grange Nature Trail	7:00am	Meet by NSPKU desk
Into the Future Treatment Research into PKU - what's in the Pipeline - Part 1: Sepiapterin	Dr Anupam Chakrapani, Consultant IMD Paediatrician, Great Ormond St Hospital NHS Foundation Trust	9.00-9.20	Kenilworth 3
Into the Future Treatment Research into PKU - what's in the Pipeline - Part 2: mRNA therapy	Prof Tarek Hiwot, Consultant Metabolic Physician, University Hospitals Birmingham NHS Trust	9.20-9.40	Kenilworth 3
European Guidelines	Prof Anita MacDonald OBE, Consultant Metabolic Dietitian, Birmingham Children's Hospital	9.40-10.20	Kenilworth 3
COFFEE BREAK & Exhibition stands		10.20-11.00	
NSPKU Campaign update	Kate Learoyd, Caroline Graham, NSPKU Campaign Team	11.00 - 11.30	Kenilworth 3
Lived Experiences of Sapropterin testing - research to guide our future	Giana de Sousa, Lead Paediatric IMD dietitian, Nottingham and NIHR researcher	11.30-11.50	Kenilworth 3
"PKU United" panel - Recognising common and unique experiences	PKU Community panellists, to be chaired by Polly O'Connor	11.50-12.35	Kenilworth 3
Questions & Panel Discussion	All Speakers	12.40-1pm	
LUNCH - Sponsored by Vitaflor & Fate		13.00-14.00	Kenilworth 1 & 2

## Notes

## Saturday 18th May Afternoon

Topic	Speaker	Time	Location
A choice of 4 workshops		14:00-16:00	
Rare Minds – Support for carers for children w PKU (adults only please, no children)	Rare Minds – Emma/Zubyda	14.00–15.15	Othello
Rare Minds – Workshop: Mental health for adults (over 18s) w PKU	Rare Minds – Emma/Zubyda	14.00–15.15	Hamlet
DROP IN style – PKU diet and the under 12s	Georgie Wood & Clare Dale (IMD Dietitians from Manchester Children's Hospital and University Hospitals, Birmingham NHS Trust)	14.00–16.15	Kenilworth Event centre Foyer
DROP IN style – Portion size/ Label/Food workshop over 12s	Birmingham Adults IMD Dietetics team, University Hospitals Birmingham NHS Trust	15.00–16.15	Kenilworth Event centre Foyer
Refreshments will be served in Kenilworth Event Foyer		15:15–16:00	
Cookery Workshop – Cooking Bites – informal	Chef Neil and Chef Devin; Chef Derek	16.15–17.15	Kenilworth 3
AGM		17.30 – 18.30	Hamlet
Children's Pyjama party		17.30–19.00	Avon
DINNER – Sponsored by Vitaflo		19.00–21.00	Kenilworth 1 & 2

## Notes

[illegible]

# Sunday 19th May

## Morning

Topic	Speaker	Time	Location
WALK AND TALK number 3	Chesford Grange Nature Trail	7:00am	Meet by NSPKU desk
Your NSPKU Website - what is there for you?	Suzanne Ford (of NSPKU)	9.00-9.30	Kenilworth 3
Psychology and Neuropsychology - Phe levels and cognitive function - how do they relate and what tasks are affected? (real life task examples)	Cristina Romani - Reader in Neuropsychology with Megan Staines of Aston University (Birmingham)	9.30-10.15	Kenilworth 3
Research PKU and Sport/exercise/physical activity	Annie Skidmore & Lewis Gough - Associate Professor in Nutrition and Physiology, of Birmingham City University	10.15-10.30	Kenilworth 3
Option for those interested: Annie Skidmore & Lewis Gough- Associate Professor in Nutrition and Physiology focus group 10.30-11am			Oberon
COFFEE BREAK	*hotel check out time is 11am	10.30-11.15	Kenilworth 3
The latest PKU Research from Birmingham Children's Hospital	Birmingham Children's Metabolic Dietitian Research Team: Dr Anne Daly, Alex Pinto (and special guest Maria Gama, Paediatric Dietitian, Southampton).	11.15-12.00	Kenilworth 3
Adults' experience of PKU clinic - findings from the NSPKU survey	Dr Fatma Ilgaz, Hacettepe University, Turkey	12.00-12.20	Kenilworth 3
Questions & Panel Discussion	All speakers	12.20-12.45	Kenilworth 1 & 2
LUNCH Sponsored by Nutricia Depart		13.00-14.00	

## Notes

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# Useful Information

## Creche & Supervised Group

- 📍 Stoneleigh
- 🕒 Sat 8:45am-5:30pm  
Sun 8:45am - 1pm

The creche and playgroup is for children age 0-8 years. It is professionally run by Bluey and Baloo. Personal information and consent forms must be completed before a child is allowed into the creche and playgroup.

## Young Adult Games Room

- 📍 Stratford
- 🕒 Friday 6pm - 10pm  
Saturday 9am - 4pm  
Sunday 9am - 1pm

## Children's Party

- 📍 Avon
- 🕒 Sat 5:30pm - 7pm

There is no supervision for this event. Children must be accompanied by a parent/carer for the duration of the event. There is no paperwork to complete for this event.

## Swimming Pool

- 📍 Located within the facility
- 🕒 Everyday until 7pm

The Swimming Pool can be used until 7pm. All children must be supervised.

## Children's Splash Times

- 📍 Located at the Swimming Pool
- 🕒 Monday to Friday 8am-11.15am  
3pm - 7pm  
(except Wednesdays 8am - 10am & 3pm - 7pm)  
Saturday & Sunday 8am-11am  
3pm - 6pm



Photography and filming will take place during the weekend which may be used in NSPKU publications, on the NSPKU website and on social media. If you do not want image of yourself to be used in this way please speak to a member of the NSPKU Council of Management.



Simply join the Wifi network with the password: [internet](#)



Check out time on your departure day is 11:00am, however luggage can be stored at reception until you are ready to leave the hotel.



Tweet your conference comments and pictures to @nspku.



Please return your lanyards to the NSPKU Welcome Desk at the end of the conference - thank you.

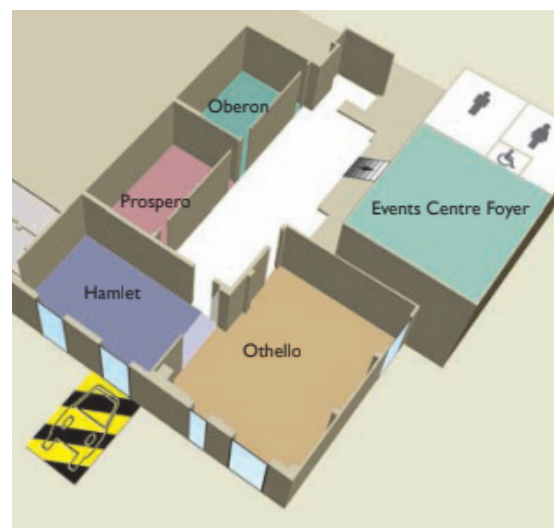
DISCLAIMER: Parents and guardians of children and any other persons related to the event or child care at the event, hereby irrevocably and unconditionally wave any claim against the NSPKU to the extent permissible by law.

# Hotel Map

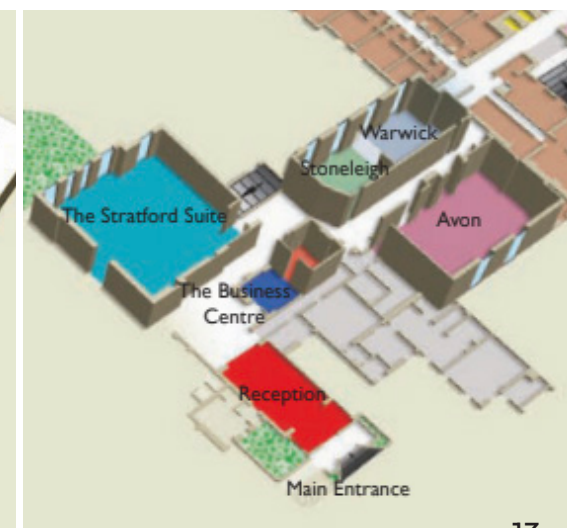
## Ground Floor



## Lower Ground Floor Shakespeare Suites



## Ground Floor





# Walk and Talk



This year we are trying out three very short “Walk and Talks”. Chesford Grange has its own short nature trail and we will be using this route.

Please all come wearing suitable footwear for walking on non-paved ground, and we would like all children under the age of 12 to be accompanied by a parent or guardian. There will be at least one NSPKU volunteer leading the walk each time and the walk will take about 30 minutes. All ages are welcome: pushchairs /buggies may work if they have all terrain wheels.



# Testimonials

“The conference is great, it’s a community, it’s supportive, there is a great deal of help and information but generally there is no stress because everyone understands what you are going through.”

James, Father of a child with PKU

“The NSPKU brings everyone together. You can talk to people with the same thing as you. Sharing your stories and experiences can reassure people as well, thats really nice to do, especially for people with new born children.”

Tesni, Adult with PKU

“They understand the little things areas important as the big treatments and campaigning to improve the quality of life of PKUs everywhere.”

Claire, Adult with PKU







# NSPKU

Thank you for supporting  
our conference

Find out more at <https://nspku.org>  
or on our socials



The National Society for Phenylketonuria (NSPKU)



NSPKU



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