

# NSPKU

## 49th Annual Conference 2022

FRIDAY 30th SEPTEMBER – SUNDAY 2nd OCTOBER



Forest Pines Spa & Golf Resort  
Broughton, North Lincolnshire

NSPKU

In association with



**GALEN**



**TARANIS**



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# NSPKU

**49th Annual Conference 2022**

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# Welcome to the NSPKU 49th Annual Conference 2022

On behalf of the NSPKU Board may I welcome you all to our 49th Annual Conference at the Forest Pines Spa & Golf Resort in Broughton, North Lincolnshire. This is the second time we have been here and some of you will remember the last – when the inclement weather prevented many from travelling.

After a two-year hiatus, we are finally able to hold a Conference on a face-to-face basis, where we can all mix and mingle and discuss all things PKU.

In this booklet we provide all you need to know about the conference. Please note the trade exhibition which is always a great place to meet with the manufacturers and quiz them over new products for PKU. We thank them all for their continued support of the NSPKU and the PKU Community.

The Conference Centre is located at the opposite end of the Hotel to your rooms. Please allow extra time to get to meals, plenary sessions, creche and so on. Do make sure you are aware of where all the relevant rooms are.

I hope you all have an enjoyable Conference meeting old friends and making new ones.

Ask not what PKU can do for you—ask what you can do for PKU!

**Especially for the NSPKU's Jubilee Anniversary in 2023.**



**Eric Lange**  
NSPKU Chair

# USEFUL INFORMATION

## CRÈCHE & SUPERVISED PLAYGROUP

- 📍 FOREST SUITE LOCATED WITHIN THE LEISURE COMPLEX
- 🕒 SAT 08:45–17:30, SUN 08:45–13.00

Consent forms are available at the NSPKU stand in the reception area and should be handed to a representative as soon as possible to ensure smooth entry to the crèche and playgroup.

The crèche and playgroup is for children age 0–8 years. It is professionally run by DBS-checked nursery nurse staff. Personal information and consent forms must be completed before a child is allowed into the crèche and playgroup.

## PARENT/CARER AND BABY ROOM

- 📍 PLOWRIGHT
- 🕒 THROUGHOUT CONFERENCE

## YOUNG ADULT GAMES ROOM

Unsupervised chill out room

- 📍 EIGHTEEN57
- 🕒 FRIDAY 18:00 – LATE
- SATURDAY 09:00 – LATE
- SUNDAY 09:00 – 13.00

## CHILDREN'S PARTY

- 📍 FOREST SUITE
- 🕒 SAT 17:30–19:00

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 LEISURE COMPLEX
- 🕒 EVERY DAY UNTIL 19:00

The Swimming Pool can be used until 19:00. Children must be supervised at all times.



**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 images of yourself to be used in this way please speak to a member of the NSPKU Council of Management.



Simply join the **WiFi** network "Hilton Honors", 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 using the future hashtag #NSPKU2022



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 waive any claim against the NSPKU to the extent permissible by applicable law.

# Programme of Events

## DAY 1 – FRIDAY 30th SEPTEMBER

TIME	PROGRAMME	LOCATION
14:00 - 18:00	<b>REGISTRATION</b> - Delegates arrive at the Forest Pines Hotel - NSPKU Welcome Desk opens	Tennyson Suite
18:00 - late	<b>Young Adults Games Room:</b> Unsupervised chill out room (closed during meal times)	Eighteen 57
19:00 - 19:30	<b>FRIDAY 30th September - Welcome Drinks Reception</b>	Tennyson Suite
19:30 - 21:00	<b>FRIDAY - Welcome Dinner Sponsored by Promin &amp; Taranis</b>	Tennyson Suite

## DAY 2 – SATURDAY 1st OCTOBER

TIME	PROGRAMME	LOCATION
07:00 - 09:00	<b>BREAKFAST</b>	Tennyson Suite
<b>DAYTIME ACTIVITIES AND ENTERTAINMENT FOR CHILDREN AND YOUNG ADULTS</b>		
08:45 - 17:30	<b>Creche</b> (Infants 0-2 years of age)	Forest Suite
	<b>Playgroup</b> (Children 3-8 years of age)	Forest Suite
Throughout Conference	<b>Parent/carer and baby room</b>	Plowright
09:00 - late	<b>Young Adults Games Room:</b> Unsupervised chill out room (closed during meal times)	Eighteen 57
09:00 - lunch	<b>Children's trip to The Deep</b> Children attending should meet at the Hotel's Main Reception. Coach departs at 9.00	Main Reception
<b>CONFERENCE PROGRAMME</b>		
09:00 - 09:40	<b>Into the Future Treatment Research into PKU - what's in the Pipeline</b> Dr Gisela Wilcox, Consultant Metabolic Physician, Northern Care Alliance NHS Foundation Trust - Salford	Newton Suite
09:40 - 10:20	<b>Into the future: Nurturing the next generation - PKU pregnancy experiences</b> Rosie Cox and Amber Shulver	Newton Suite
10:20 - 11:00	<b>Coffee/Tea Break</b> - Low Protein food manufacturer exhibitions stands will be open	
11:00 - 11:30	<b>NSPKU Campaign update with Liz Twist</b> Kate Learoyd, Caroline Graham and Special Guest Liz Twist	Newton Suite
11:30 - 12:15	<b>PKU Journeys - Common ground, Ups and Downs, What can the NSPKU learn and how can we help?</b> Group of people living with PKU and Duncan Noble-Nesbitt as Chair (to include parents of children with PKU)	Newton Suite
12:15 - 12:45	<b>Panel Discussions; meet Chris Riches (Daily Express)</b> All Speakers from the morning session	Newton Suite
13:00 - 14:00	<b>LUNCH</b> - Sponsored by VitaFlo and Fate Quick-Fire Raffle	Tennyson Suite

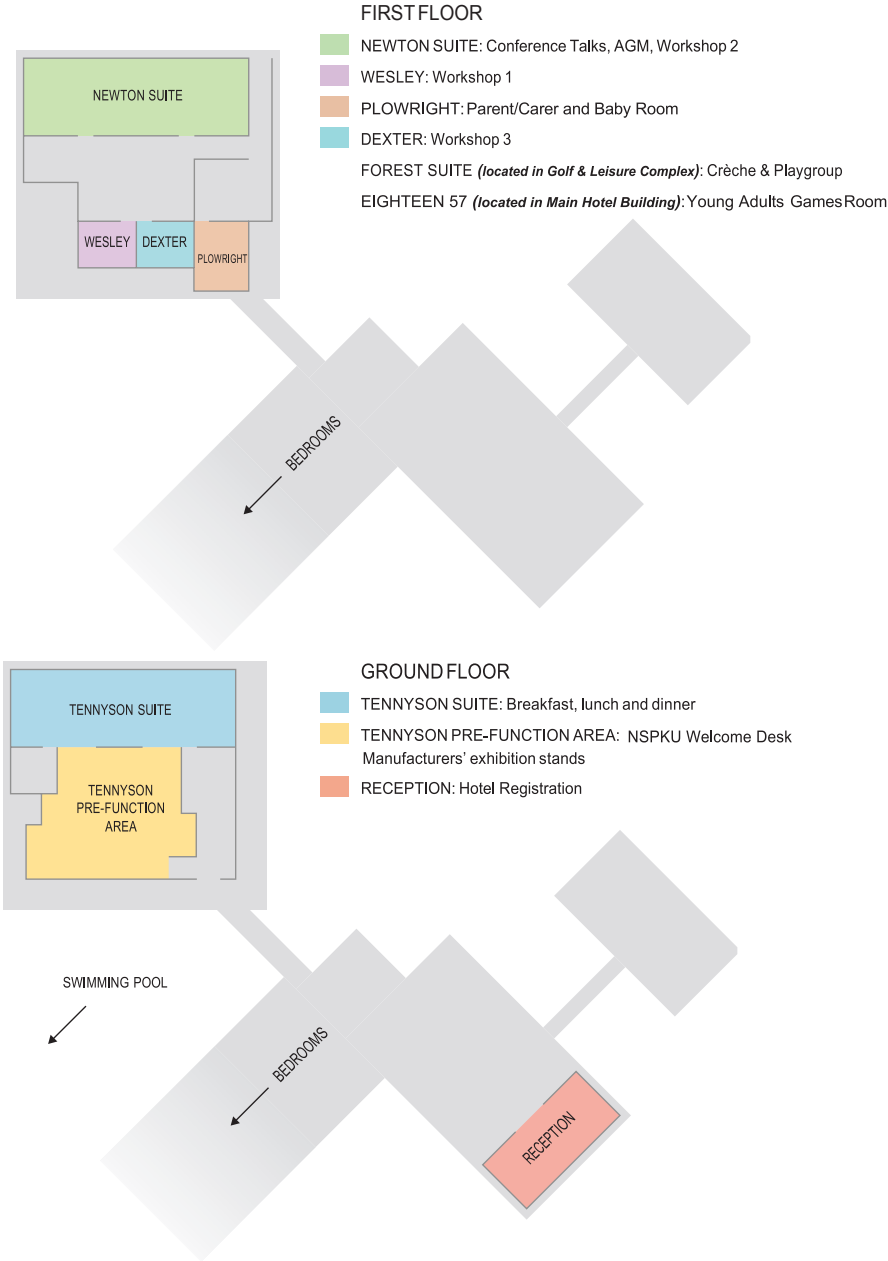
## DAY 2 cont. – SATURDAY 1st OCTOBER

TIME	PROGRAMME	LOCATION
	<b>WORKSHOPS:</b> Workshops will be repeated so you will have the opportunity to attend two	
14:10 - 14:55	<b>Workshop 1: Bloodspots - How to do them!</b> Nicky Mumford, Clinical Nurse Specialist, Great Ormond Street Hospital, NHS Foundation Trust	Wesley
	<b>Workshop 2: Guess the portion size/Label Reading/Food workshop</b> Barbara Cochrane, Specialist Metabolic Dietitian, Royal Hospital for Sick Children, Glasgow	Newton
	<b>Workshop 3: PKU Bites App - What's Next for the App?</b> Sharon Evans, Birmingham Children's Hospital	Dexter
15:00 - 15:45	<b>WORKSHOPS: Repeated</b>	
	<b>Workshop 1: Bloodspots - How to do them!</b> Nicky Mumford, Clinical Nurse Specialist, Great Ormond Street Hospital, NHS Foundation Trust	Wesley
	<b>Workshop 2: Guess the portion size/Label Reading/Food workshop</b> Barbara Cochrane, Specialist Metabolic Dietitian, Royal Hospital for Sick Children, Glasgow	Newton
	<b>Workshop 3: PKU Bites App - What's Next for the App?</b> Sharon Evans, Birmingham Children's Hospital	Dexter
15:45 - 16:15	<b>Coffee/Tea Break</b> - Low Protein food manufacturer exhibitions stands will be open	
16:15 - 17:15	<b>Cookery Workshop - Cooking Bites: Fun, informal and interactive cookery demos</b> Chef Devin (Mevalia), Chef Derek (Nutricia) and Chef Neil (VitaFlo)	Newton Suite
<b>EVENING PROGRAMME AND ENTERTAINMENT</b>		
17:30 - 18:30	<b>NSPKU ANNUAL GENERAL MEETING</b> - Everyone welcome	Newton Suite
17:30 - 19:00	<b>CHILDREN'S PARTY</b> - with Magic Show	Forest Suite
19:30 - 21:00	<b>DINNER</b> - Sponsored by Mevalia	Tennyson Suite
21:00 - 00:00	<b>EVENING ENTERTAINMENT</b> - music provided by Party Nights Disco	Tennyson Suite

# Programme of Events

DAY 3 – SUNDAY 2nd OCTOBER		
TIME	PROGRAMME	LOCATION
07:00 - 09:00	BREAKFAST	Tennyson Suite
DAYTIME ACTIVITIES AND ENTERTAINMENT FOR CHILDREN AND YOUNG ADULTS		
08:45 - 13:00	Creche (Infants 0-2 years of age)	Forest Suite
	Playgroup (Children 3-8 years of age)	Forest Suite
	Parent/carer and baby room	Plowright
Throughout Conference	Parent/carer and baby room	Plowright
09:00 - 13:00	Young Adults Games Room: Unsupervised chill out room	Eighteen 57
CONFERENCE PROGRAMME		
09:00 - 09:30	Genetics and PKU Rebecca Whittington, Principal Clinical Scientist Bristol, Genomics Laboratory	Newton Suite
09:30 - 10:15	Sapropterin in Children and Adults Professor Anita MacDonald, Consultant Metabolic Dietitian and Diane Green, Advanced Clinical Practitioner	Newton Suite
10:15 - 11:00	Coffee/Tea Break - Low Protein food manufacturer exhibitions stands will be open	
11:00 - 11:30	Collecting and Analysing blood - dried blood spots and capitainers Rachel Carling, Consultant Chemical Pathologist, Viapath Lab & Chair of MetBionet	Newton Suite
11:30 - 12:30	Research Bites from Birmingham Children's Hospital PKU Research Team Professor Anita MacDonald, Consultant Metabolic Dietitian and Team: Dr Anne Daly and Alex Pinto	Newton Suite
12:30 - 12:45	Questions & Panel Discussion All speakers from the morning session	Newton Suite
13:00 - 14:00	LUNCH - Sponsored by Nutricia	Tennyson Suite
DEPART		

# Hotel Map





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Innovation in Nutrition

# NS PKU

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