

WHST PRESENTS



you
ROCK
fest

Celebrating

25
Years

#YouRock

**You're invited to the
Wolf Hirshhorn Syndrome
Trust National Meeting**

3 – 5 May 2019

**A chance for WHS families to get
together and share experiences**

This year our event is a celebration
of **ALL TYPES OF MUSIC** and you
because:

- All WHS families are STARS and the work that you do often goes unrecognized
- Our WHS children are beautiful little STARS and most of them love music
- It enables us to all get together for a social gathering and explore music in different forms
- This is not just about Music but about you, because **YOU ROCK!**



The event is open to ALL Wolf Hirschhorn Syndrome families.

This pack includes information about the event – what's on when and what you need to do next to book your place. Please make sure you read it carefully and provide all the necessary information in the booking form, so we can ensure your weekend runs as smoothly as possible.

Any queries about the National Meeting please contact **Sarah Fleming** on nationalmeeting@whs4pminus.co.uk or 07796 678478.



**WOLF
HIRSCHHORN
SYNDROME
TRUST**

National Meeting
3 – 5 May 2019



Venue:

DoubleTree by Hilton,
Paradise Way, Walsgrave
Triangle, Coventry, CV2 2ST

20% off

pre-ordered drinks
for Saturday night.

A form will be sent to you
once you have confirmed
your attendance.

Warm cookie on arrival!
FREE Parking
Hoist available

WHST subsidised accommodation rates:

If you are a family of three or more, you may wish to consider booking interconnecting family rooms.

Fri night Twin or Double room	£85 - includes breakfast.
Fri night Family room (interconnecting)	£130 - includes breakfast
Sat night Twin or Double room	£71
Sat night Family room (interconnecting)	£102
Sun night Twin or Double room	£85 - includes breakfast.
Sun night Family room (interconnecting)	£130 - includes breakfast

Breakfast on Sunday morning will be paid for by The Trust for WHS child/adult, siblings under 18 plus two adults per WHS child. There are a lot of rooms that can also accommodate an additional bed if you do not want interconnecting rooms. Bedrooms are on allocation until **Friday 5th April 2019**. After this date, you will not be able to access the WHST discount. The Hotel Cancellation Policy on allocation bedrooms is 12 midnight the night prior to the date of arrival so book now and if you need to cancel nearer the time due to illness, you can with no costs incurred!

Please confirm your attendance at the event on the attached form and return to Sarah Fleming on sarah_abra@hotmail.com or 9 Church Close, Maids Moreton, Buckingham, MK18 1QG by 1st December 2018.

You will then be sent a code that will entitle you to the discounted WHST accommodation rate when you call the hotel to book your room.

National Meeting 3 – 5 May 2019



Itinerary Overview

Friday 3rd May

Arrival and free time

Arrival and evening to socialise. Spa facilities on site.

Saturday 4th May

9am	Arrival	
10am - 12 noon	Conference	Adults
10am – 12 noon	Umbanda Drumming Workshop Group 1 (free)	WHS/Siblings
10am – 12 noon	Crèche (free)	WHS/Siblings
12.30 - 1.30pm	Lunch	ALL
1.30pm - 4pm	Conference	Adults
1.30pm – 5pm	Crèche (free)	WHS/Siblings
1.30pm – 4pm	Bowling (£8)	WHS/Siblings
2pm – 4pm	Umbanda Drumming Workshop Group 2 (free)	WHS/Siblings
4.15pm - 5pm	Parade	WHS/Siblings
5-6pm	Free Time	ALL
6pm	Fancy Dress Competition	ALL
6.30pm	Dinner	ALL
8pm – 8.30pm	WHST's Got Talent	ALL
8.30pm - Midnight	Karaoke/Disco	ALL

Sunday 5th May

10am - 2pm	Family Fun Day – see pages 7-9 for more information	OPEN TO FAMILY & FRIENDS
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National Meeting
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Sat 4th May 2019
National Meeting -
The Conference

Planning a Financially Secure Future – The Mencap Trust Company Ltd

Julie Schwarz, Director of Mencap Trust Company will be presenting on Will and Trust options and Mencap Trust services to ensure you can plan a financially secure future for your young or older children. You will also be able to make an appointment to speak to Julie 1:1 if you wish, to discuss personal circumstances or find out further information.

Seizure Genetics and Seizure Management in WHS

Karen Ho is Principal Scientist at Translational Research, Lineagen, Inc. and Scientific Advisory Board Member of several rare disease groups (4p-Support Group, Liv4theCure, KBG Syndrome, NGLY1.org, RUN, Utah Rare). Karen will present the results of a survey of antiepileptic drug responses providing insights into the link between genetics and the type of antiepileptic drug that will provide the best response.

Support for Family Members Caring for Adults and Children with WHS - Katherine Vogt


Katherine Vogt is a researcher at Sheffield University. She has identified from interviews with UK parents, that there is a huge gap in support for family members caring for adults and children with WHS and has subsequently carried out a research report into the support provided and what is actually needed. She will present her research findings and the recommendations made as well as provide families with the opportunity to discuss them.

Dr Alisdair McNeil

Senior Clinical Research Fellow, University of Sheffield Honorary Consultant in Clinical Genetics, Sheffield Children's Hospital. Alisdair will be taking over the reins from Dr Oliver Quarrell and will present on WHS genetics to **new-to-event attendees** and those who would like a refresher. Dr Oliver Quarrell will be joining us on Saturday too, so if you have any specific questions for him there will be the chance to speak to him directly.

Round Table Discussions

We will be running a round table discussion session giving you the chance to discuss key subjects with other parents and share your experiences. You can choose from a range of different topics, some of which we hope will be led by external support organisations. Topics could include:

- Dealing with the diagnosis - led by 
- WHS and the single parent
- Dealing with difficult behavior
- Coping with stress
- WHS and feeding difficulties

National Meeting
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Sat 4th May 2019
National Meeting
highlights

Bowling

1.30pm – 4pm, **£8 for 1 game**. Open to siblings and WHS, 9yrs+

The chance to go bowling in Coventry for siblings and some WHS children who choose not to attend the crèche during the afternoon. Those going bowling will need to be escorted by a parent or carer. Any snacks or drinks required are to be provided or sufficient funds to purchase them at the bowling alley must be provided.



Fancy Dress Competition

6pm

After such a success last year, we're kicking off the evening with a Rock or Pop Star fancy dress competition for all children. Adults are encouraged to dress up too for the evening as their favourite Rock or Pop Star!

There are prizes for the best boys and best girls costume!
Here are a few photos from last year's competition.



National Meeting
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Sat 4th May 2019
National Meeting
highlights include

WHST's Got Talent

8pm – 8.30pm

We know You Rock (that's why we're putting on YouRockFest) but this is your opportunity to show us that you rock! If you have a talent for singing, for comedy, for dancing, for magic we have a spot for you to perform! We already have some WHST talent lined up to perform! It's gonna Rock!



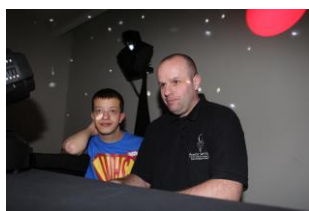
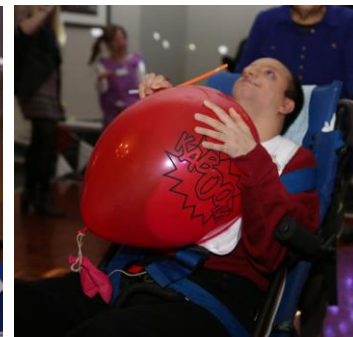
Karaoke/Disco

8.30pm – Midnight

Time for everyone's favourite part of the weekend!

Disco dance the night away with your WHS family and friends.

Don't forget to take a photo in the selfie in this year's photo booth!



National Meeting
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The crèche
Sat 4th May
10am – 5pm

Crèche

The crèche will be available all day Saturday and will include a **Drumming Workshop by Umbanda** – please see below for more details.

The crèche will be run by The Mobile Crèche Company. To find out more about them please visit www.mobilecreche.com – this has all the latest information for parents about the service that they provide.

There is **no charge** for your child to attend the crèche. Please confirm your child's attendance and Carer's attendance (if required) on the form on the link below: <http://www.mobilecreche.com/eventbookingform/EVENT-20171219-1614.html>

The crèche is for all ages and there will be activities available for older WHS children too. Please register your child if you do not wish them to be in the main conference room with you, so that the crèche team can allocate staff to co-ordinate activities for them (and entertain them).

The crèche is open to all children including siblings.



The Umbanda Drumming Workshops

Music provides an opportunity for children to work, learn and respond emotionally and intellectually.

With ten years experience in the therapeutic field, Umbanda offer therapeutic music workshops that are fun and interactive. Umbanda recognise that 'play' and 'primary creativity' develop our relationship with the world. Music transcends many restrictions and the shared experience of group and solo drumming is accessible to all.

The drumming workshops will culminate in a parade and performance at the end of the day!



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National Meeting
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Sunday 5th May
Family Fun Day
and concert

Open to friends and family so please invite them along



Music workshops

Entertainment



Stalls

**BBQ
AND**

MORE!



Cake Stall

If you can, please bring a cake for us to sell on the day. They can be home made or purchased.

Please do not bring any cakes that require refrigeration or any containers or plates that you wish to keep. Clearly mark the type of cake that it is, if it is homemade and indicate any cakes that have nuts in them.

Please hand your cake in upon arrival on Friday evening or Saturday morning.

Tombola and Raffle

We will be having a tombola and raffle as well this year, so please bring donations for these if you can. We are extending it to include bottles, jars, toys, unwanted gifts, and sweets this year (please ensure bottles, jars and sweets are within date).

Please hand your donations in upon arrival on Friday evening or Saturday morning.



National Meeting
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Sunday 5th May
Family Fun Day
and concert

Open to friends and family so please invite them along



Sunday 10am
FREE!

The **Singing Hands** performance will be an interactive, multi-sensory, Makaton-signed experience featuring many of the much-loved songs from the **Singing Hands** DVDs and CDs.

Join in as they jump like kangaroos in Australia, wade through the jungle in Africa looking for wild animals or as they go on a day trip to the zoo and the farm!

Or dance to the up-tempo pop songs themed around the concepts of friendship and happiness!

So come and sing, sign, dance and experience their unique show!

Designed to be fully-inclusive, the session can be enjoyed by children (and parents!) of ALL ages and abilities.



Meet & Greet opportunity! Have your photo taken with Suzanne and Tracy or get their autograph after their performance!



National Meeting
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Sunday 5th May
Family Fun Day
Music Workshops



MUSIC WORKSHOPS

Sunday

10am – 11am
11am – 12noon
12 noon – 1pm

FREE!

Limited spaces available. Must be booked in advance.

Please complete the form at the back to confirm the session you would like if you wish to attend one of them.

These exciting sessions run by Soundabout will appeal to those who like using gadgets to make music and manipulate sound using **cutting-edge technology**. Skoogs, Soundbeams and iPads will be used to create playful music together. If you have an iPad please bring it along, though it's not essential - everything will be supplied.

Open to the whole family.



DANCE SESSION

Sunday

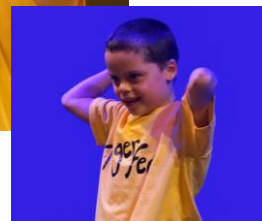
11.20am – 12noon

FREE!

Embodiment is a fun, friendly and inclusive dance company set up with the aim to give everybody the chance to dance.

Embodiment will be running a Tiger Feet session giving us all the opportunity to enjoy music and dance together. The class will guide us through specially constructed routines using many exciting props that fire our imaginations and creativity.

Open to the whole family.



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MEALS

Meals

WHST will pay for meals for two accompanying adults per WHS child / WHS adult, all WHS children and all siblings under 18 years of age at the following times:

- Saturday lunch
- Saturday dinner
- Sunday breakfast
- Sunday lunch

You are responsible for paying for all other meals and for meals at these times for additional adults and siblings over 18. Please note, breakfast on Saturday is included in the subsidised Friday night accommodation rate. Additional meals cost:

- | | |
|--------------------------|----------------------------------|
| • Adult Saturday lunch | £16 |
| • Adult Saturday dinner | £17.50 |
| • Adult Sunday breakfast | £7 |
| • Adult Sunday lunch | To be paid on the day at the BBQ |

Please indicate how many additional meals you require and supply payment for these when you register to attend the event – details are on the registration form.

Teas and coffees will be provided during the conference.



Please note any special requests regarding accommodation and/or meals should be addressed directly to the hotel at the time of booking.

There are lifts at the Hotel and there will be a hoist available for you to use provided by the Trust.

20% discount on pre-ordered drinks for Saturday night. A form will be emailed to you once you have registered for the event.



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National Meeting
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Register to attend
today!

Yes we are attending the National Meeting 2018!

Family Details:

Surname: _____
Address: _____

Postcode: _____
Tel: _____
Email: _____

Please include an email address

Number of family members attending: _____
It's our first time attending: Yes _____ No _____

WHS Child/Adult details:

	Name	Age	Meal (adult or child)
1.	_____	_____	_____
2.	_____	_____	_____
3.	_____	_____	_____

All other family members (and/or carers) attending:

	Name	Age	Meal (adult or child)
1.	_____	_____	_____
2.	_____	_____	_____
3.	_____	_____	_____
4.	_____	_____	_____
5.	_____	_____	_____
6.	_____	_____	_____
7.	_____	_____	_____

Days attending: Friday _____ Saturday _____ Sunday _____

If you are attending only one day please state if you are staying overnight Friday and / or Saturday
Friday _____ Saturday _____

Carer attending Conference on Saturday or looking after WHS Child(ren)
Conference _____ Child(ren) _____

It's our first time attending Yes _____ No _____



National Meeting 3 – 5 May 2019



Register to attend
today!

Activities (please complete those that apply)

Bowling 9yrs+ @ £8.00 per person Saturday afternoon

Name(s) and ages of children (please print)

Name:

Yes please

Age:

Parent/Carer(s) attending

Name:

Sounds Modern (FREE) Sunday

Yes please

Please indicate which session is your preferred session (1 – 3 with 1 being most preferred):

- 10am – 11am _____
11am – 12noon _____
12noon – 1pm _____

PAYMENT for Bowling and Additional Meals

Please enclose payment for:

1. Bowling @ £8 per person Yes (please tick) _____ Amount enclosed/paid _____

2. Additional meals

WHST will pay for meals for two accompanying adults per WHS child / WHS adult, all WHS children/adults and all siblings under 18 years of age

- | | | | |
|--------------------------|--------|-----------------|-------|
| • Adult Saturday lunch | £16 | Number required | _____ |
| • Adult Saturday dinner | £17.50 | Number required | _____ |
| • Adult Sunday breakfast | £7 | Number required | _____ |
| • Adult Sunday lunch | tbc | Number required | _____ |

TOTAL to pay £ _____

Please return the completed form to Sarah Fleming at 9 Church Close, Maids Moreton, Buckingham MK18 1QG or nationalmeeting@whs4pminus.co.uk, along with your payment (cheques should be made payable to Wolf Hirschhorn Syndrome Trust or you can pay online – details below):

- Account Name: WHST
- Sort code: 82-11-07
- Account number: 60509784

If you would like to attend but require financial assistance in order to do so, or wish to be removed from the WHST mailing list, please contact Stephen D'Allenger-Bradshaw on chair@whs4pminus.co.uk or 07860 446502.



National Meeting
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Order your t-shirts
today!



Mens

Size:	S	M	L	XL	2XL
Chest (to fit):	34/36	38/40	42/44	46/48	50/52

Ladies

Size:	S	M	L	XL	2XL
	8/10	10/12	12/14	14/16	18/20

Child

Size:	XS	S	M	L	XL
Age:	3-4	5-6	7-8	9-11	12-13
Chest (to fit):	30	32	34	36	38

T-shirts

Please enclose payment for t-shirts @ £7 each.

Family Name: _____

Please indicate the number of each size and colour (red or black) required:

	<u>Black</u>	<u>Red</u>
Child XS	_____	_____
Child S	_____	_____
Child M	_____	_____
Child L	_____	_____
Child XL	_____	_____

	<u>Black</u>	<u>Red</u>
Ladies XS	_____	_____
Ladies S	_____	_____
Ladies M	_____	_____
Ladies L	_____	_____
Ladies XL	_____	_____
Ladies 2XL	_____	_____

	<u>Black</u>	<u>Red</u>
Mens XS	_____	_____
Mens S	_____	_____
Mens M	_____	_____
Mens L	_____	_____
Mens XL	_____	_____
Mens 2XL	_____	_____

Total amount enclosed/paid: £ _____

Please return the completed form to Sarah Fleming to 9 Church Close, Maids Moreton, Buckingham MK18 1QG or nationalmeeting@whs4pminus.co.uk, along with your payment (cheques should be made payable to Wolf Hirschhorn Syndrome Trust or you can pay online – details below):

- Account Name: WHST
- Sort code: 82-11-07
- Account number: 60509784

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WHS Child/
Adult Biog

Put your WHS child on the Wall of Fame at the National Meeting



Please provide an up-dated biog of your WHS child/adult and they will feature on the Wall of Fame at the National Meeting and assist in our records for future research.

Name: _____

Date of birth: _____

Gender: M _____ F _____

Genetic diagnosis: _____

Likes/loves: _____

Achievements: _____

Key medical history: _____

Please attach or email a recent photo.

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Photo consent form

Please send this back with your completed registration form

We plan to take photographs/videos of families during the course of the weekend and some may be used for marketing purposes to promote the Wolf Hirschhorn Syndrome Trust. Please confirm your approval (or otherwise) for your child to be photographed/videoed and for them to feature in marketing materials:

I do/do not (please delete as appropriate) give my permission for photographs/videos to be taken.

I do/do not (please delete as appropriate) give my permission for photographs/videos of my family to be used for marketing purposes.

If you are taking your own photographs/videos at the National Meeting, please respect the privacy of others and do not make their photographs public without being certain that individuals pictured are happy for their images to be published.

Thank you!

Signature of parent/carers:

Name of parent/carers (please print):

Date:
