









## FAMILY WEEKEND CONFERENCE

### SATURDAY PROGRAMME

| Time                      | Activity   | Location  |
|---------------------------|--|---|
| 08.15-9.00 a.m.           | Breakfast  | Dining Room   |
| 9.00-5.30 p.m.            | <b>Kids at Heart</b> Creche open<br>(For pre-booked children up to age 12 only)  | Reading & Writing<br>Rooms                            |
| 9.00-10.00 a.m.           | <b>Registration</b> for Saturday day only delegates  | Reception area  |
| 10.00 a.m.<br>- 4.00 p.m. | <b>Information stands</b> open   | Butterley Hall 1                                      |
| 9.30-9.45 a.m.            | <b>Opening remarks</b><br>Mark Sanderson, Vice Chair AF<br>Daniel Hill, Trustee AF, on our international interests & events including <b>Welcome</b> to Antoine Gliksohn, <b>Albinism Europe</b>   | Butterley Hall 2                                      |
| 9.45-10.45 a.m.           | <b>Main session B:</b><br><b>From the lab to the clinic and back</b><br><b>– what is the latest in albinism research?</b><br>Dr Helena Lee, University of Southampton & Univ. Hospital   | Butterley Hall 2                                      |
|                           | <b>Sessions for Children &amp; Young People:</b>   | See separate pages                                    |
| 10.45-11.30 a.m.          | Refreshment break & <b>Information stands</b> visit  | Main House Bar &<br>Butterley Hall 2                  |
| 11.30 a.m.<br>-12.30 p.m. | <b>Optional sessions:</b><br>4) Benefits and you<br>Charlotte Throssell, Disability Direct<br>5) Understanding Anxiety<br>Vaijayanti Drumm, Drumm Training & Development<br>6) Getting the most out of UK based &<br>international activities and how VICTA can help<br>Tracie Tappenden, CEO, VICTA | Butterley Hall 2<br>Butterley Hall 1<br>The Book Room |
|                           | <b>Sessions for Children &amp; Young People:</b>   | See separate pages                                    |

## FAMILY WEEKEND CONFERENCE

### SATURDAY CONTINUED

|                 |   |   |
|-----------------|---|---|
| 12.45-2.15 p.m. | Lunch and <b>Information stands</b> visit   | Dining Room &<br>Butterley Hall 1                         |
| 2.15-3.30 p.m.  | <b>Main session C:</b><br>Special Education Issues & EHC Plans<br>Maria Bloom, Legal team trainer, IPSEA  | Butterley Hall 2  |
|                 | <b>OR Main session D:</b><br>Confidence & Assertiveness<br>Vaijayanti Drumm, Drumm Training & Development   | Butterley Hall 1  |
|                 | <b>Sessions for Children &amp; Young People:</b>  | See separate pages  |
| 3.30-4.15 p.m.  | Refreshment break & <b>Information stands</b> visit   | Main House Bar &<br>Butterley Hall 1                      |
| 4.15-5.30 p.m.  | <b>Optional sessions:</b><br>7) UK, European & Global Perspectives on Albinism<br>Antoine Gliksohn, Albinism Europe & Robin Spinks, RNIB<br>8) The Dance of Chance: an interactive way of explaining the pattern of inheritance of OCA1 and OCA2<br>Dr Patricia Lund, Coventry University<br>9) Understanding Nystagmus & update<br>Sue Ricketts, Nystagmus Network | The Book Room<br><br>Butterley Hall 2<br>Butterley Hall 1 |
|                 | <b>Sessions for Children &amp; Young People:</b>  | See separate pages  |
| 5.30-6.15 p.m.  | Singing from Ben Haynes   | Main House Bar  |
| 6.15-7.15 p.m.  | <b>Dinner</b> (self-service style)  | Dining Room   |
| 7.30-9.30 p.m.  | <b>Family entertainment</b> family quiz, children's<br>Super Heroes fancy dress- adults <i>optional</i> , raffle/auction & music from Ben Hayes & Ozan Erder<br><br>There will be a basic bar open until 9.30 p.m. in the hall and the Main House Bar will be open afterwards until 11.00 p.m.  | Butterley Halls 1&2                                       |

## **FAMILY WEEKEND CONFERENCE**

### **INFORMATION STANDS** (Saturday only)

We are grateful to the following exhibitors for being an important part of the event.

#### **Goalball UK**

[www.goalballuk.com](http://www.goalballuk.com)

Governing body for the sport within the United Kingdom. Includes development plan, events calendar, mailing lists, and contacts.

#### **Guide Dogs**

[www.guidedogs.org.uk](http://www.guidedogs.org.uk)

Providing mobility for the blind and partially sighted. Supporting research, raising awareness and campaigning for the visually impaired.

#### **Humanware**

[www.humanware.com](http://www.humanware.com)

For over 25 years, HumanWare's inspirational vision has resulted in a range of highly intuitive and intelligent solutions that empower people who are blind or with low vision by giving them the independence to participate effectively within a sighted world

#### **Nystagmus Network**

[www.nystagmusnet.org](http://www.nystagmusnet.org)

The leading patient information, support and scientific research charity for nystagmus in Europe.

#### **Optelec**

[www.uk.optelec.com](http://www.uk.optelec.com)

Develops products for visual impairment - low vision. Optelec products help the visually impaired to live an independent and full life.

#### **S W Retail – IC Vision Ltd.**

**INVITED**

[www.icswretail.co.uk](http://www.icswretail.co.uk)

SW Retail - IC Vision Limited is a family run business and supplies Magnifying Products and Low Vision aids for the partially sighted.

#### **VICTA**

[www.victa.org.uk](http://www.victa.org.uk)

VICTA supports children and young people who are blind or partially sighted and their families across the UK.

#### **Vision Aid**

[www.visionaid.co.uk](http://www.visionaid.co.uk)

We offer a wide range of vision aids for people affected by low vision. Browse our website and find the perfect vision aid to help you to continue to maintain your independence and continue to read. If there's something you require but can't find on our website give us a call on 01775 711 977

## FAMILY WEEKEND CONFERENCE

### SUNDAY PROGRAMME

| Time             | Activity  | Location           |
|------------------|---|--------------------|
| 08.15-9.00 a.m.  | Breakfast   | Dining Room        |
| 9.00-9.30 a.m.   | Albinism Fellowship:<br>2017 Annual General Meeting   | Butterley Hall 2   |
| 9.00 a.m.        | <b>Kids at Heart</b> Creche open  | Reading & Writing  |
| -12.45 p.m.      | (For pre-booked children up to age 12 only)   | Rooms              |
| 9.30-10.30 a.m.  | <b>Discussion Groups:</b>   |                    |
|                  | 1) Parents, Grandparents & Families   | Butterley Hall 2   |
|                  | Facilitators: Akeel Bari, Jo Bennett & Pinar Erder, AF Trustees   |                    |
|                  | 2) Adults with Albinism   | The Book Room      |
|                  | Facilitators: Rosie Dempsey, Daniel Hill, Karina Lang, AF Trustees  |                    |
|                  | <b>Sessions for Children &amp; Young People:</b>  | See separate pages |
| 10.30-11.00 a.m. | Refreshment break   | Main House Bar     |
| 11.00 a.m.       | <b>Main Session E:</b>  | Butterley Hall 2   |
| -12.00 p.m.      | Transport & Mobility Solutions of the Future<br>for persons with Albinism   |                    |
|                  | Robin Spinks, Principal Manager, Digital Accessibility, RNIB &<br>Jamie Chan Pensley, Principal Technologist,<br>Transport Systems Catapult |                    |
|                  | <b>Sessions for Children &amp; Young People:</b>  | See separate pages |
| 12.00-12.30 p.m. | <b>Closing remarks</b>  | Butterley Hall 2   |
|                  | Mark Sanderson, Vice-Chair AF<br>& Roselle Potts, Chair AF  |                    |
| 12.45-1.45 p.m.  | Lunch   | Dining Room        |
| 2.00 p.m.        | Depart  |                    |



## FAMILY WEEKEND CONFERENCE

### OTHER THINGS WE THOUGHT YOU WOULD LIKE TO KNOW

#### Other groups

We will be sharing the venue with five church groups and a writer's conference. Please respect that these other groups are sharing the centre this weekend.

#### Water safety & door hazards

Water- **Please be aware**- there are two lakes on site. One large and fairly deep. The other small and shallow. They are situated at the bottom end of the site next to the Lakeside building and near the football field.

Glass doors- There are also some fully glass doors in the areas of the venue especially the reception and bar/ lounge area. Whilst every effort is made to make these visible please be aware of the hazard.

#### Sports hall footwear

We will be using a large sports hall on Saturday including for demonstrations and practices of Goalball. If you wish to participate, please note that **black soled trainers/ pumps are NOT allowed** in the hall. Please wear alternatives.

#### Bar and alcohol

There will be a basic bar open from 7.30-9.30pm in the Butterley Hall on Friday and Saturday evenings during our conference programme.

Also, the Main House Bar usually opens before dinner early evening and until 11pm.

We know you will respect this is a family orientated event and use both facilities sensibly.

#### Photography

Photos will be taken by AF and by Positive Exposure. If you do not wish to be in any photography, which may be used by us for to help promote our work, please let the photographers know.

#### Wi-fi

There is wi-fi available in the communal areas of the venue. Please ask the Hayes Reception for details if needed.

#### Taxis

We understand a local taxi firm is Amber Taxis on 01773 836100.

## FAMILY WEEKEND CONFERENCE

### CHILDREN & YOUNG PEOPLE

**FRIDAY** **Please note:** All activities must be pre-booked. Numbers are limited.

| When?   | This...   | OR...this?   | OR...this?  | OR...this?   |
|---|---|--|---|--|
| 3.00-4.15 p.m.  | <b>What does albinism mean to me? Sharing experience and tips to cope</b><br>Ahmina Akhtar,<br>Emily Wheeler,<br>Changing Faces<br>(Guide age 7/8-12)<br>Butterley Hall 1 | <b>Circus Skills</b><br>Bezerkaz<br>Circus<br>(Ages mixed)<br>The Chapel | <b>Rap and Beat Box workshop</b><br>(Guide age 11-17)<br>Sports Hall,<br>Derbyshire Suite | <b>Kids at Heart Creche</b><br>Reading &<br>Writing<br>Rooms |
| We will explore your experience of living with albinism and encourage you to share and learn with others in a fun way. We will look at a range of strategies to help you manage unwanted attention and hopefully help you to come up with some ideas for your own toolkit. Ahmina & Emily.  |   | BLANK  | BLANK   |  |
| 4.30-5.30 p.m.  | BLANK   | <b>Circus Skills</b><br>Bezerkaz<br>Circus<br>(Ages mixed)<br>The Chapel | <b>Rap and Beat Box workshop</b><br>(Guide age 6-11)<br>Sports Hall,<br>Derbyshire Suite  |  |
| <b>Creche Times (for pre-booked children aged up to 12 only)</b>  |   |  |   |  |
| Our professionally run creche is again run by Kids at Heart <a href="http://www.kidsatheart.co.uk">www.kidsatheart.co.uk</a> A massive thanks to Julie Shaw and her team.   |   |  |   |  |
| <b>Friday</b>   | 2.00-5.45 p.m.  |  |   |  |
| <b>Saturday</b>   | 9.00-5.30 p.m. ( <b>excluding</b> Lunch 1.00-2.00 p.m.)   |  |   |  |
| <b>Sunday</b>   | 9.00-12.45 p.m.   |  |   |  |
| <b>PARENTS-</b> WHEN NOT SIGNED INTO THE CRECHE OR AT SUPERVISED ACTIVITY <b>YOUR CHILDREN ARE YOUR RESPONSIBILITY.</b><br><b>Please remember:</b> Sign your children in and out. Handover your registration forms. Give your contact details. Collect them on time. Our creche staff are amazing but need and deserve a break too. <i>Say thank you!</i> |   |  |   |  |

## FAMILY WEEKEND CONFERENCE

### CHILDREN & YOUNG PEOPLE

**SATURDAY – Please note: All activities must be pre-booked. Numbers limited.**

| When?                     | This...   | OR...this?   | Or...this?   |
|---------------------------|---|--|--|
| 9.30-10.45 a.m.           | <p><b>Managing Wellbeing</b><br/>(Guide age 11 years +)<br/>Vaijayanti Drumm,<br/>Drumm Training &amp;<br/>Development<br/>Butterley Hall 1</p> <p>OR</p> <p><b>The Detective Project</b><br/>Crime Scene<br/>Investigation -<br/>Workshop 1 - (Guide<br/>ages 8/9 years)<br/>Main House Lounge</p> | <p><b>The Running Line</b><br/>(All ages)<br/>Loughborough<br/>University colleagues<br/>Outdoors (Football<br/>field)- if bad weather<br/>possibly Sports Hall,<br/>Derbyshire Suite</p> <p><b>Sessions:</b><br/>a) 10.00 - 10.45 a.m.<br/>b) 10.55 - 11.40 a.m.<br/>c) 11.50 a.m. - 12.30<br/>p.m.</p>                               | <p><b>Kids at Heart<br/>Creche</b><br/>Reading &amp;<br/>Writing Rooms</p> |
| 11.30 a.m.-<br>12.30 p.m. | <p><b>The Detective Project</b><br/>Crime Scene<br/>Investigation -<br/>Workshop 2 - (Guide<br/>ages 6/7 years)<br/>Main House Lounge</p>   |  |  |
| 2.15-3.30 p.m.            | <p>The Detective Project<br/>Crime Scene<br/>Investigation -<br/>Workshop 3 - (Guide<br/>ages 10/11 years)<br/>Main House Lounge</p>  | <p><b>Introduction to<br/>Goalball</b><br/>(Under 13, over 13 &amp;<br/>adults- 3 sessions)<br/>Goalball UK<br/>colleagues<br/>Sports Hall, Derbyshire<br/>Suite</p> <p><b>Sessions:</b><br/>a) 2.00 - 3.00 p.m.<br/>(Guide age 13-17)<br/>b) 3.30 - 4.30 p.m.<br/>(Guide age 7-13)<br/>c) 4.30 - 5.30 p.m.<br/>(Guide age 17/18+)</p> |  |
| 4.15-5.30 p.m.            | <p>The Detective Project<br/>Crime Scene<br/>Investigation -<br/>Workshop 4 - (Guide<br/>ages 12-17 years)<br/>Main House Lounge</p>  |  |  |

## FAMILY WEEKEND CONFERENCE

### CHILDREN & YOUNG PEOPLE

**SUNDAY** **Please note:** All activities must be pre-booked. Numbers are limited.

| When?                     | This...  | OR...this?  | OR...this?   |
|---------------------------|--|---|--|
| 9.00-10.30 a.m.           | <b>Dance workshop</b><br>Nugent Education Ltd.<br>(Guide age 6-11)<br>Butterley Hall 1 | BLANK   | <b>Kids at Heart Creche</b><br>Reading & Writing Rooms |
| 11.00 a.m.-<br>12.30 p.m. | <b>African Drumming</b><br>Nugent Education Ltd.<br>(All ages)<br>Main House Lounge    | <b>Dance workshop</b><br>Nugent Education Ltd.<br>(Guide age 11-17)<br>Butterley Hall 1 |  |

## FAMILY WEEKEND CONFERENCE

### SESSION OVERVIEWS - FRIDAY

#### **Main session A: Positive Exposure global albinism photography project - *Rick Guidotti***

Positive Exposure utilizes photography, film and narrative to transform public perceptions of people living with genetic, physical, intellectual and behavioural differences. Our educational and advocacy programs reach around the globe to promote a more inclusive, compassionate world where differences are celebrated we teach everything that happiness is a choice not a result.

The statistics to support our work are staggering. With one out of five children in the United States born with a disability, the need for society to understand and respect children and adults living with genetic, physical, intellectual and behavioural differences is critical. This fascinating story started with albinism in 1998.

#### **Optional session 1: Basics of Albinism - *Jay Self***

Ophthalmologist Jay Self will provide a basic overview of albinism for those new to the condition or those requiring a refresher.

#### **Optional session 2: Stress Bucket - *Vaijayanti Drumm***

What is stress and why does it happen? Managing stress: practical insights, tools and techniques. Early warning signs of stress. Coping strategies

### **Optional session 3: Visual Impairment and Sensory Processing Disorder – is this what causes ‘Blindism’s’? - Audrey Darby**

OT's are specialists in Sensory Processing difficulties, and it has come clear to us over the past number of years that Visual Impairment causes imbalances in the sensory systems, and therefore in smooth sensory processing. This presentation will look at: What is sensory processing?

What is sensory processing disorder in relation to children with a visual impairment? – is this different to ‘Blindisms’ How do we recognise sensory processing disorder?

What can we do to help?

Children who have difficulties in this area will or may act out, seem stubborn, perhaps not listen to instruction, or carry out repetitive behaviours.

### **Evening session: The Blindfold Challenge – Suzanne Carr**

Suzanne Carr of Guide Dogs will oversee a series of fun family activities helping us to understand what sight loss can mean for everyday tasks. Themes will include:

Food: - buttering bread, finding the right tin for dinner, labelling and using other senses (smells). Communication awareness:- Communicating to someone in blindfold to complete a task. Mobility:- Looking at different canes and techniques of sighted guiding. Finding things:- Identifying coins and using the systematic search technique.

## **SATURDAY MORNING**

### **Main session B: From the lab to the clinic and back – what is the latest in albinism research? – Helena Lee**

Currently, there are no treatments for the eye problems seen in albinism. The average vision in albinism at 20/80, is below UK driving standards, which has implications for school, work and social life. This is why finding a treatment that can improve eyesight in albinism, was named as a priority by the Sight Loss and Vision Priority Setting Partnership in 2013.

There is a lot that we do not understand about exactly why eye problems develop in albinism, and why the degree of visual impairment can vary enormously amongst individuals with albinism. The recent revolution in genomics and eye imaging technology has expanded our understanding of this condition and has opened up exciting new possibilities for treatment. In this talk, we will explore what we have learned about albinism and the eye in recent years and how we are using this information to develop new treatments that will improve eyesight in individuals affected by albinism.

### **Optional session 4: Benefits and you – *Charlotte Throssel***

An overview of the disability related benefits and how they may affect you and your loved ones. A very flexible session that will give you chance to ask questions.

### **Optional session 5: Understanding Anxiety - *Vaijayanti Drumm***

This workshop is aimed at anyone who would like to understand how anxiety issues develop, how it affects our mental and physical health, and ways of managing anxiety more affectively and positively.

- Understanding our anxiety
- Fight or flight
- Breathing techniques
- Negative and Positive thinking

### **Optional session 6: Getting the most out of UK based & international activities and how VICTA can help – *Tracie Tappenden***

Come and find out what amazing opportunities VICTA offers to families, children and young people. From life changing experiences to places like Thailand, Sicily, the International Computer Camp in Croatia to sleeping over at the Natural History Museum and our ever-famous family weekends, there is something for everyone. The session will be broken down to include something fun, something sweet and something serious!

## **SATURDAY AFTERNOON**

### **Main Session C: Special Education Needs & EHC Plans – *Maria Bloom***

Independent Parental Special Education Advice specialist Maria Bloom will provide an overview for parents on how to get the most from the SEN system for their child and how to engage effectively with Education, Care & Health Plans.

### **Main Session D: Confidence and Assertiveness – *Vaijayanti Drumm***

This workshop is designed to help individuals who want to be more confident, learn skills to help communicate effectively in the workplace, socially, with family and friends. It is useful for individuals who would like to make changes to their lives, improve self- confidence and self- awareness and take steps on the road to success.

- What is confidence and assertiveness
- Difficulties that arise with lack of confidence
- Behaviour types- passivity, assertion, aggression
- Body Language. Thinking assertively, saying no

**Optional session 7: UK, European & Global Perspectives on Albinism –  
*Antoine Gliksohn & Robin Spinks***

Antoine and Robin will share their perspectives on albinism around the world and Antoine on progress with the development of a European network for the albinism community and how best to engage with it.

**Optional session 8: The dance of chance: an interactive way of explaining the pattern of inheritance of OCA1 and OCA2 – *Patricia Lund***

I will require audience participation! Volunteers welcome please. I would like to encourage young people to attend this session. This fun way of informing us about the inheritance of albinism will no doubt include drums and dancing!

**Optional session 9: Understanding Nystagmus & Update – Sue Ricketts**

The Fellowship has always had strong connection with Nystagmus Network as nystagmus affects most people with albinism. Sue is welcomed back to provide an understanding of nystagmus and update on developments.

**SUNDAY****Main Session E: Transport and Mobility Solutions of the Future for persons with Albinism – Robin Spinks & Jamie Chan Pensley**

In this thought provoking and interactive session, Jamie and Robin will explore some of the transport and mobility solutions of the future for persons with Albinism.

They'll present an honest and realistic assessment of the rapid progress of Connected Autonomous Vehicles (CAVs) and they'll attempt to answer the when, why and how of self-driving cars drawing upon industry knowledge and experience with a wide range of stakeholders.

The session will also consider the impact and potential for independence from Mobility as a Service and smart ticketing. Also considered will be the impact of wearable technology and personalisation.

Finally, the session will consider the rapid rise of E Bikes and their appropriateness as a safe and sustainable mobility solution for persons with low vision.



**Save the Date!**

**Albinism Fellowship**

**Family Weekend**

**Conference**

**2019**

**Friday 18<sup>th</sup> – Sunday 20<sup>th</sup>**

**October 2019**

**(Provisional)**

**Venue to be confirmed**