

Bringing the outside in

CIAT's Social and Community Challenge was launched in November 2014 to harness members' skills for the wider benefit of society. Nicola Miller MCIAT reports on the story so far.



Playing outdoors: a simple pleasure denied to children suffering from *Xeroderma Pigmentosum*

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In November 2014 we held the first meeting for the Institute's inaugural Social and Community Challenge. As it was a pilot initiative it was difficult to imagine how this might go and where it might lead.

This year's chosen Project is to work in conjunction with registered charity, Teddington Trust to develop a ultraviolet(UV) safe universal shelter for patients affected by a very rare and life limiting condition called Xeroderma Pigmentosum(XP), allowing them to spend time 'outside' within the safety of a protective UV filtering bubble/shelter.

After introductions from the team, which comprised volunteering Members that responded to the call in AT Magazine, social media and press promotion, there was an opening welcome and overview of the project brief from Membership Group Chair and Teddington Trust Co-founder Nicola Miller MCIAT. This was followed by a short but very informative

presentation from Sally Turner, Outreach Nurse from the UK's only specialist XP Clinic at Guys and St Thomas Hospital, London.

Some exciting initial concept ideas emerged. A decision was also made to engage with student members as it would allow the Challenge to access the diverse

Responses from student members were encouraging, with a good calibre of applicants from both the UK and Europe

pool of knowledge offered by our future Architectural Technology professionals and give them an opportunity to become involved in the project. Actions were noted and the team dispersed to follow

up on their respective areas of investigation.

Responses from student members were encouraging, with a good calibre of applicants from both the UK and Europe. We shortlisted four students who we felt could add value to the project and who we could support in terms of their direction of study.

Following press and industry coverage of the initiative and the work of Teddington Trust which ran in parallel, other interested professionals stepped forward to lend their time and expertise. The team assembled at CIAT for a second time at the end of January.

The buzz and energy in this session was fantastic and as both a CIAT professional and with a vested interest in the design outcome, (my own son affected by XP), I came away utterly inspired and very hopefully that the seeds of ideas tabled at this meeting will lead onto a tangible

design outcome which will provide considerable benefit worldwide to children and families affected by XP.

The Project is divided into two strands that will focus on both a temporary 'pop-up' solution to be flexible and lightweight, affording the user the opportunity to enjoy multiply locations with this travel shelter, and a more fixed version for erection at a home, nursery, or school setting. A key aim, in addition to achieving complete protection from UVA and UVB, is to produce a design that will allow the user to gain sensory enjoyment from the setting, ie the grass or sand underfoot, and that it should be affordable for use globally, in diverse economic regions.

As the design phase continues it is the vision of the design team that a series of physical and virtual models will be built before commissioning prototypes, and hopefully funding streams can be secured to see the Project progress to medical endorsement, implementation and ultimately final design and delivery to the users.

'The founding of Teddington Trust was the knee-jerk reaction of my husband and I to the heartache and feeling of helplessness at our nephew's diagnosis (aged just 13 months old),' said Rebecca Stewart, founder of Teddington Trust. 'I could never have believed that three years on it would lead me to a room full

of brilliantly talented professionals and enthused students working together on a project set to revolutionise outside spaces for XP sufferers everywhere.

'I can't express how grateful we are that the Institute and so many individuals have given their time and energy to date to this Safe Gardens project'.

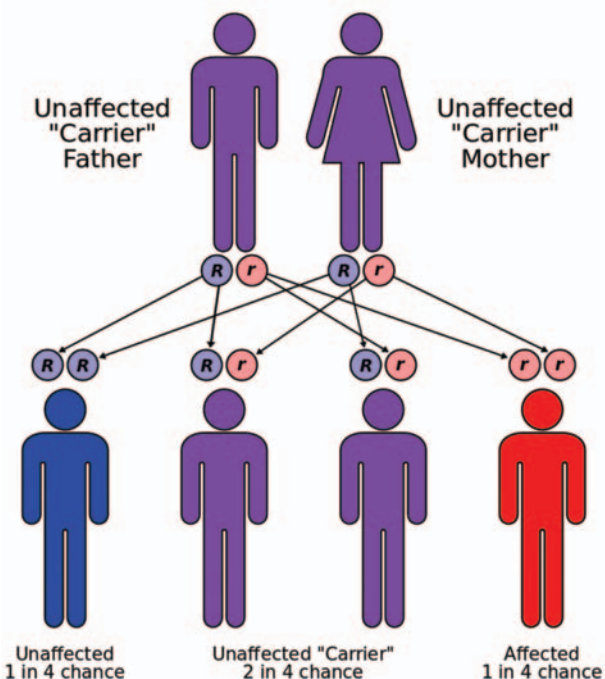
Hiva Fassihi, Clinical Lead at UK National XP Service added 'Protection from Ultraviolet Radiation (UVR) in sunlight has a significant impact on morbidity and mortality in XP. Children with XP can develop skin cancers as early as four years of age if not meticulously protected.

'The Safe Garden Project aims to develop UVR free shelters, both temporary and permanent, for children and adults with XP. It is a unique and innovative idea which will make a huge impact on the quality of life of individuals with XP, allowing them to enjoy life in a safe environment. The UK National XP Service multidisciplinary team wholly supports this important project.'

To find out more about this Safe Garden Project contact Nicola Miller MCIAT: support@teddingtontrust.com
Or to find out how to nominate your Project for the next Social and Community Challenge in 2016 contact James Banks, Membership Director: james@ciat.org.uk

'I am proud to be a part of this exciting project. To date we have explored some really exciting ideas that have the potential to improve the lives of not only Edison, but other children around the world that suffer with XP. The opportunity to make use of our skills to help others is really motivating and rewarding'.

***Daniel Owen ACIAT,
LSI Architects LLP.***



How XP is transmitted. *Credit: C.Burnett*

Xeroderma Pigmentosum: What is it?

Xeroderma Pigmentosum is a genetic condition which affects less than 100 people in the UK. It is a DNA repair disorder, whereby the patient's ability to repair damage caused by UV light is deficient.

Patients with XP cannot go outside, unprotected during daylight hours and are also affected by many types of artificial lighting, making them 10,000 times more susceptible to aggressive skin cancers than the general population.

To learn more about XP go to www.teddingtontrust.wordpress.com or follow Teddington Trust on Facebook and Twitter.