



a GLIMPSE *of our* WORLD

*Inspirational Stories by
Young Deafblind People*





Ruairi's

STORY

My name is Ruairi Corr and I have been deafblind since the age of 6 and a half years old as a consequence of a rare genetic illness called Adrenoleukodystrophy. Some people have heard about it because the boy in the film Lorenzo's Oil also had it. I started life living in Ireland going to mainstream school but, following a bone marrow transplant to arrest my Adrenoleukodystrophy, I became deafblind. My family moved to England so that I could go to the school for the blind in Exeter.

It took many years for me to adjust to my new life with disabilities, especially when I had experienced how different it is for people with full hearing and sight. It was frustrating and made me very sad, but it didn't rob me of my determination and tenacity for life. With the support of my family and friends, I climbed the 3 peaks and Carrantuohill which is the highest mountain in Ireland.

My biggest challenge was to train and run the half marathon in Exeter in 2011 and again in 2012. The training was so incredibly difficult and boring but I was determined to do it. I ran both runs with a sighted guide and in 2012 finished ahead of some people in running clubs, in 2 hours 22 minutes. Quite an achievement considering I am also epileptic and steroid dependent and actually ended up in the High Dependency Unit of our local hospital for 4 days after the 2012 run with electrolyte imbalance.

The thing I was most pleased about was that the sponsorship money raised was enough to build a house for a blind man in Malawi called Isaiah that my sister met doing voluntary work there. Prior to that he and his family lived in a terrible mud hut with a high malaria risk. Isaiah now lives in a house with a proper roof and windows and it has changed the lives of all of his family.

My next challenge is to climb the longest wooden staircase in the world, the Flørlø Steps in Norway. There are 4444 steps altogether!! Who knows what the next challenge will be after that!



Andrew's

STORY

My story begins in Dagata Village, Lasi County, Romania. I was born into a poor family and was the only child with disabilities. Since my birth I was diagnosed with blindness and other health problems. Within my family, with my mother, my father and brothers, Ionut and Mihai, I was surrounded with joy every day of my early childhood. I was really a happy child until the age of four when my father passed away. After he died the word 'home' was replaced by a long series of placement centres / foster homes for children with disabilities. My mother could not afford to sustain us financially anymore.

When I was seven I came to 'Moldova' Special High School, a school for visually impaired children. Being there made me feel like being at home. I remember I cried so much when I got there and I was very sad, but I got used with things around me in a short time. I met a real family, extraordinary people who were there for me and they still are. I learned from them what love, dedication, kindness and joy are, I made friends and I cannot believe how fast time passed. I remember the first plush toys, geometric shapes and puzzles, things that helped me to explore the world around me.

In September 2004, at the age of 15, I found out I would be transferred to a special class for deafblind children. I still see the beautiful and gentle face of my first teacher, Gabriela, in the crowd, squeezing between dreams Years passed. I am a grown up boy now and, instead of my toys forgotten in a corner, I learn new and interesting things every day which have helped me to become who I am today - a respectful, sociable and big hearted young man. I would like to become a chef and maybe this will happen for me. I am now 20 and I enjoy being with my friends. I am sure our relationships will never fade away. I thank God for the chance he gave me.



Hansha's

STORY

I was born into a family in the remote village of Dhanki in Gujarat, India. Profoundly deaf, with low vision and learning disabilities, I was not what the village was used to seeing in their children and was soon branded as the God's curse. My family was shunned. My special educator helped me to understand the environment and I began responding. Very soon I could count with beads and do simple arithmetic. I took over the household chores and helped my mother. I began communicating in sign language and a new medium of conversation and expression opened up for me. My educator supported me and enrolled me in the local school and very soon I was spelling my name in English amongst other things.

It took a while for the reality to seep in to the mindset of the villagers but slowly and firmly the community was swept by the winds of change. Farmers began employing my parents again in the fields and in fact got impressed by my abilities as well. I became a coveted farm hand. I have also formed a band of friends from the neighbourhood.

I am registered under Govt. of India's 'Mahatma Gandhi National Rural Employment Guarantee scheme which aims at enhancing the livelihood and security of people in rural areas. Recently, my family also built their own home under the Govt. of India's social welfare programme 'Indira Awaas Yojana'.

Today I own a shop with the support from Sense International India's Income generation activity plan. I run the shop with the support of my mother and earn around Rs. 500 (approximately £7) per day. Thus I am contributing to the family income and supporting my family.

The pain and hurt in my Father's eyes are a thing of the past. Heartfelt pride and a new set of aspirations for the future have taken their place.



Costel's

STORY

I grew up in a large family, being the second child. Shortly after my birth, my mother realised I could not see very well and so I had eye surgery. After I had spent a lot of wonderful moments with my brothers and my mother in my country village, I had to go to school. So I got to go to 'Moldova' Special High School, a school for visually impaired children where I am still studying.

I was a very shy boy in the early years of school. I used to hide my eyes when someone looked at me. I was always a quiet boy, due to my mother and my teachers. I haven't changed and I am very proud to be like this. Since I was a little boy I have been interested in learning things about people, animals, plants, mountains, Romanian history.... about the world.

I like everything. For example, maths gave me headaches but reading and writing became familiar to me when I was in the 5th Grade. I love listening to stories and writing compositions about almost everything (on the computer, of course). My schoolmates love me for my altruism and my jokes. My teachers like me for being a good student and a quiet boy. All the years I spent in this school, with good and less good things, I faced a lot of challenges. I destroyed barriers that sometimes I thought I could not go through. Now that I am older, I still have strong feelings and my heart goes

crazy when I remember myself telling my first poem in front of my schoolmates. I was 0in the 3rd Grade. I remember my wonderful adventures such as trips with my teachers, new experiences such as my first omelette cooked in our Gastronomy Lab, me being shaved for the first time and ironing a shirt in the studio for Independent Life Skills. I love cars and would like to drive one very much although it seems I will have to limit myself to discovering only what there is inside of a car. I will turn 18 in two months and I will have a big party. I invite you and you are welcome!



Raj's

STORY

My name is Raj and I am 22 years old. I have USHER Syndrome and a hearing impairment since birth. I started losing my vision when I was 13 years old. I had to drop out of mainstream school but my zest for life did not die. I continued my further studies at the School for the Blind with support from the Deafblind Unit supported by Sense International India. When I reached my 10th board examination year, it was very challenging for me, my family and teachers. My teachers taught me all the subjects using CCTV and large print material. My writer was also instructed to speak in a slow pace but loud tone, using some signs, etc. After sheer hard work by my teachers and my family, I passed Secondary School Board Examination with excellent marks.

I also cleared Higher Secondary Board Examination with Arts subjects. I then attended a course on scientific massage of the Blind People Association's Vocational Training programme and was recruited as class room assistant by the centre to assist in training other students.

I wanted to be independent and support my family. Considering my skills, I received financial support under the Income Generation Activity of Sense International India to start my independent practice in scientific massage. I opened my Massage centre on 29th May 2014 at my own house. I am now an earning member of my family and they are proud of my achievements.



Zaakirah's

STORY



My name is Zaakirah, in Arabic it means the hereafter. I was born in Fort Lauderdale, Florida, on December 20th, 1992, almost 4 weeks prematurely. When I was 9 months old, I was diagnosed with Retinoblastoma. Shortly after, my right eye was surgically removed. Since then I have had a prosthetic eye. As a result of chemotherapy, I lost my hearing which resulting in a mild hearing loss which declines to this day so I also wear hearing aids in both ears.

My mother celebrated my birthday every year even if there was a year I did not want too. It was a reminder that I was special, that I had greater purpose, and that my life is worth valuing. It was not until I chose to tell people, the right people, that I am a cancer survivor. Then I started hearing loving phrases like "You are so inspiring", "You are a miracle" "You are amazing", and then it clicked that my purpose in life is to inspire.

My parents always made sure I believed that there is a bigger world out there than the world we live in. It was not until high school that I received my first opportunity to travel out of country to really see that for myself. Before, I was narrow minded about expanding my travels due to thoughts of not being safe because of my disabilities or because of the types of people in this world.

The first country I visited was Costa Rica, with a group for deaf, hard of hearing, and sign language enthusiasts.

That was such a great experience and I felt so comfortable and it opened up another opportunity for me. Shortly after that, I travelled as a student ambassador on a two week European tour through the U.K, France and Italy. The most life changing travel experience was when I went to Ghana after high school for two months in the summer on a volunteer service trip. Our group stayed with a home stay family.

This summer, I am planning my first independent endeavour and photographic excursion to Senegambia. The goal is to give back by teaching photography to the youth and sharing what I learned from them upon my return through photos and a short film. With all the lemons life has given me, I feel ready to conquer the challenges and accomplish, fulfilling my destiny. Life could be worse but I am forever grateful to be a survivor.

Alistair's

STORY

My name is Alistair Milne and I have had quite a severe visual impairment since birth. I also have cerebral palsy which means that I need to be fully supported by my moulded wheelchair and my pusher (I think this is quite funny!).

I am 18 and left school last year and I have been a member of the One Giant Leap project since it started in November 2010.

I live with my mum and Gran in Glasgow and this helps with being central to a lot of activities.

It can be quite frustrating for me to make my views known. I have adapted to using a switch facility but I can effectively communicate using my facial expressions with people who know me well. I am quite a cheeky chap, especially with the ladies.

I am very keen on music and, with lots of support with specific adapted musical instruments; I have been involved in performing in a group to a large audience which included my family. I am very proud of this, especially as this was along with my friends who I have built up really good relationships with.

My biggest challenge was being involved in our recently acquired community allotment. With support, I was able to plant the seedlings, transfer them to the allocated area and provide care to them until the vegetables, etc. were ready for picking. The thing I was most pleased about was that when the different varieties of fruit and vegetables were ready to be picked, I was able to share them with the whole group

My next challenge is to further develop my music skills so that I can become part of a larger music concert which will help raise funds for other good causes and to be part of the development of a future market garden with the hope of providing food for food banks.



Christina's

STORY

My name is Christina Ortiz and I am a twenty year old Hispanic American who lives in Florida. When I was two years old, I was diagnosed with Neurofibromatosis Type II, a genetic disorder that I inherited from my father. This disorder causes a mutation in my genes that resulted in various tumors, and, as such, my vision is fairly poor and my hearing is nearly nonexistent.

I had my first surgery at seven years old, to remove a tumor from the top of my head, and then I had brain surgery at ten and again at age eleven, both of which resulted in a significant amount of hearing loss. When I entered high school, I could barely manage to get through my classes most days. This led to me missing a great deal of school and if it wasn't for the fact that I was sick and disabled, I probably would have been kicked out.

I managed to graduate with honors with the rest of my class at the age of seventeen. It was a struggle though, especially since I had begun chemotherapy treatments the summer before my senior year. As a result of nearly a years' worth of chemo and the toll it took out on both my mind and body, I was forced to pull out of my classes and switch to home schooling in order to finish the credits.

I've started classes in the Honors Institute and have joined Phi Theta Kappa, an honors society for students that recognizes and encourages scholarship amongst two year university students. I am also getting more active, though when it comes to volunteering, I always have to contact agencies beforehand and make sure that being hard of hearing won't cause any issues. Most people are thrilled to work with me, however. I just set up a schedule with the local library in order to volunteer with them on a weekly basis.

I'm also going to Ghana in May with a small group of six other students and one professor. We will be spending a week working in the orphanage there and then spending an additional two days in the capital learning about the slave trade. Even though I am hard of hearing, the professor has been very accommodating and is willing to help me in any way that she can. I am honored to have been chosen to go and have this experience.



I hope to graduate by the spring of 2015 and then I'll be having yet more brain surgery done. This will wipe out what little hearing I have remaining in order to save me from the risk of facial paralysis. Once I graduate and recover from that surgery though, I want to transfer to Gallaudet University in Washington D.C. I feel that going to a Deaf university is the best way to improve my ASL since I really want to become part of the Deaf community.

I aim to major in history so that I can become a historical researcher. An advanced degree is usually required in this field, so once I finish my Bachelor's Degree, I'll be reapplying to school in order to begin my Master's Degree in History. By that point,

I hope that I will be fluent in ASL and can attend college wherever I want, so long as they have a decent disability department that can supply me with the accommodation I require to achieve my goal. Right now, my first choice for my Master's Degree is Carnegie Mellon University which is a research university in Philadelphia.

At this time though, I am just trying to take life one day at a time since thinking about the future in too much detail can be stressful. I read on an almost constant basis. I watch television shows when I can remember that they are on. I help my little brothers with homework and other things and spend as much time with them as I can, since I'm not sure how often I will see them once I transfer. I look up new vegetarian recipes and try out the ones with ingredients I can afford. I go to the movies with my best friend. I dance in my room when I am by myself to nothing but the music that plays in my head, even though my movements can be clumsy and awkward since the spinal cord surgery caused damage to my left leg.

I may not do anything dramatic and life altering but that does not matter. I am still living my life as it suits me despite what drawbacks my disability and hearing impairment may try to force on me.

Enita's

STORY

My name is Enita Chamba, I am eighteen years old and I live in Chikhwawa, Malawi. This is about 40km from the commercial city of Blantyre. I lost my sight and hearing senses at a very tender age due to severe sickness. My family is chronically poor and illiterate. I did not go to school until a time when VIHEMA discovered me. VIHEMA is a specialist association in Malawi that provides social and economical support for deafblind people.

VIHEMA understood my situation and decided the best way to help me. I was sent to a School for the Deafblind for a basic education since I had passed the recommended age for primary and early child development education. As such I could not finish all the grades for upper classes. In the process of searching for a more convenient and rewarding career, I opted for an entrepreneurship and VIHEMA facilitated my studies in business management skills. I managed to grasp some skills and VIHEMA provided me with an agricultural entrepreneurship. This educated me in livestock keeping which provided me with a small commercial income. Today I am successful rearing goats and running a small tuck shop with stocks such as sugar, bathing soap, salt, matches and many other groceries. In my view I believe that a deafblind person can perform just as good as any other person who is normal and able bodied.



Aarne's

STORY



Hello, I am Aarne Pirkola and am 25 years old. I live in Espoo, Finland. At present, I am a student of massage at Keskuspuisto Vocational College in Helsinki. I have had Usher Syndrome since birth. My first language is Finnish Sign Language. I also use tactile sign language and can write and read Braille.

My hobby's include swimming, tandem biking, running with a guide, playing chess and the gym. I like to read books, watch films, cook food at home, travel aboard and hike in the forest.

I have three sisters and one brother. My parents and three sisters all hear and they can use sign language. My brother like me has Usher Syndrome.

My parents noticed that I could not hear when I was baby. They brought me to the doctor. The doctor diagnosed deafness. The doctor encouraged my parents to study Finnish Sign Language.

I started attending the Deaf school in Oulu in autumn 1995. I lived in the dormitory from Monday to Friday because my home-city Pyhajoki is a distance of 100 km to Oulu. I was at home at weekends. The school life was usually nice. I made lots of friends at school.

I had not noticed and I did not know about my sight problem at school. But I noticed that I sometimes bumped into my friends.

I went to a meeting of hearing and visually impaired children when I was 9 years old. Their special ophthalmologist researched my eyes and found that I have Usher Syndrome.

I actively participate in youth meetings and summer camps of deafblind young people. There I get to meet my peers and we exchange information and experiences. I get support also from the rehabilitation adviser who helps me to get education and vocation. The Finnish Deafblind Association is a very important organization for me because this organization supports deafblind people and helps them to be equal in society.

In 2005, I studied at Mikael High school and graduated in 2009. I then studied customer service at Keskuspuisto Arla vocational college 2009 to 2012. Keskuspuisto Arla is a good school specially for visually impaired people. In Keskuspuisto Arla, after studying customer service, I decided to study for a new career as a professional masseur. I graduated in this profession on 13th July 2014 and I will found a massage business.

In the future, I am very interested in being an activist for deafblind people similar to myself. It is my dream to participate in many national and international deafblind events and conferences.

Lisa's

STORY

Hi, my name is Lisa and I am 23 years old. I was born deaf and last year found out I have Ushers. The doctor said it was very rare and not many people, including my GP, have heard of it. I was born deaf so I am used to my deafness, however, my eyes have been my eyes and ears and now to find out I will lose my sight is terrifying. I lost my side vision and am totally blind in the dark (night blindness). My mum brought me up teaching me to talk and put me into a mainstream school, ignoring all the people who told her I belong in a deaf school. She wanted me to be able to choose between the hearing and deaf worlds.

When I got diagnosed, I felt very scared and alone and so did my parents especially as we had no help or information. I was driving but, because of my Ushers and being put on the blind register, I am not allowed to drive anymore which really hurt me as that was my bit of freedom taken away from me. I did feel very depressed and cried a lot. Someone told me there was a place that can help called DeafBlind Scotland and they have been so helpful and caring so we did not feel so alone. Without Deafblind Scotland, I will still be in my room crying with no confidence. They helped me and my family come to terms with Ushers and help start to build my confidence.

I wanted to raise funds for Deafblind Scotland and raise much needed awareness for Ushers. In April last year, I freestyle abseiled off Edinburgh Forth Rail Bridge and raised £300. I hosted a coffee morning in November and raised a further £470. I am continuing my fundraising and raising awareness into 2014 with bucket collecting at a local football ground, supermarket packing and the Glasgow Half Marathon, hopefully with my dad.

I was very upset that I had Ushers but I decided not to let it take over my life. I do not know what is going to happen in the future but I do know I am going live my life to the fullest, no matter what. I am lucky that I have amazing friends, family and support. Follow your heart and dreams no matter what anyone tells you. I may not hear or see as well as other people but I can do just as much as them and nothing or no one can stand in my way.



Marian's

STORY

My name is Marian and I am a student in the tenth grade of the Special Vocational School "PPNeveanu". I am eighteen years old and I am of Roma ethnicity diagnosed with profound bilateral hearing loss associated with bipyramidal syndrome. I was born in Galati to a large family of eight members. I am the second child in the family and I have got five brothers and one sister. The financial situation and living conditions in childhood were at the poverty line. Due to insufficient living space (a room and a hallway), we got sick often. Repeated hospitalisations caused me anxiety and regression because I lacked my family's love and safety.

One of the worst experiences was at ten years old when, after a complicated fracture, a prolonged hospitalisation period caused me to have panic attacks. When I got out from the hospital, I became a different person separated from the surrounding world. I was fearful, afraid to communicate with anyone, sitting alone, withdrawn and not wanting to interact. With the help and support of my family and school staff, the counsellors have managed to help me overtake the difficult moments in my life.

Now I consider myself to be a sociable person who is practical, wanting to be helpful and eager to learn new things. I help my family every day, especially my mother who works at a social canteen as a volunteer to enable us to provide for daily living. I love telling stories, joking with my brothers and my colleagues.

Along with the staff of the school I have participated in various extracurricular activities like drawing competitions, artistic creation (where we produce decorative objects which are then capitalised), Celebrations, trips and a school choir with sign language interpretation.

My wish for the future is to stay close to my family and friends and find a suitable job to prove that I am able to work.

Ricky's

STORY



I am a graduate of the Helen Keller National Center (HKNC) in Port Washington, New York. This is a world renowned school for the deaf blind. They work with people who are hard of hearing or totally deaf with any amount of vision loss. I was a student from April 2011 through to March 2012 and the Helen Keller National Center really changed my life for the better.

I attended other Centers for the blind but, in the late '90s, I experienced minor hearing loss. I was told about the HKNC many times so, when I was running out of options, I decided to give it a chance and I am glad that I did. They give lots of one-to-one training that helps deafblind individuals live a productive life and, most importantly, to take charge of their lives.

HKNC has deafblind students from all over the world. They have many class options and I was able to take a sign language course. At first, I didn't not have the desire to take it because I figured it would not help me when it came to getting a job. But once I got into it, I realised that was not true. The class helped me communicate with other students who had no hearing at all. I was even able to practice with people who had some hearing.

During my training, I had the privilege to go to some of HKNC's tech seminars which was a big help in guiding the deaf blind to communicate. CLC was a communica-

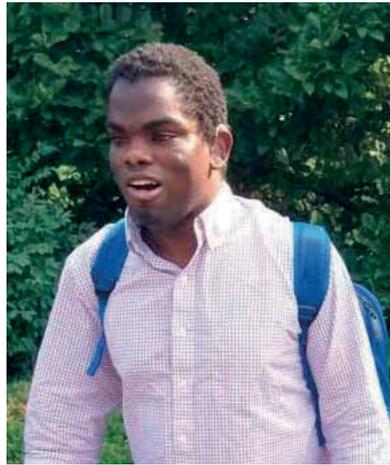
tions course that taught communications skills including social, Braille, spelling and many other areas that help someone communicate.

Job readiness played a major part in my education. I did temporary reception work at the HKNC's switchboard, transferring calls to the proper departments. I also worked at a physical therapy center scheduling appointments and taking messages. Using my musical talent, I was able to volunteer playing the piano at a group home. As a student, you get a chance to try different jobs to show your ability. They also had mock interviews to help you improve on your interview skills, just as the job club did at CVI. We got to have informational interviews with employers which helped us learn what employers are looking for.

I write all of this to show how HKNC inspired me. As a board member of the Georgia Association of the Deaf Blind, I encourage and talk to future students about going to HKNC. I see much interest even in the Georgia community. I could not say enough thank you's to the HKNC training and residence staff for what they have done and continue to do. When you come to HKNC, you will learn how to live a productive life and be good leaders for your families, communities, your nation and our world. Which, of course, all goes back to the example Helen Keller strived to set with her own life.

George's

STORY



I became deafblind in the November of my senior year of high school. I had been blind, of course, since the age of two, and my hearing had begun its progressive decline by the time I was 4, due to retinal blastoma and radiation treatments. "He's blind," my family would introduce me; "I'm visually impaired," I explained. Also a family friend's rather unsparing presented me to a neighbor as "Blind and half deaf." Mainly, though, the brilliance of my blindness seemed to blind people, so that I had often to physically point to my hearing aids to break their myopia, not that I especially wanted too. That I was getting deafer yearly was, for me and my family and teachers, an inconvenient and worrying truth, to be handled with minimal fanfare, better hearing aids, louder voices, higher volumes but no fuss.

This pretense fell apart the farther I progressed in high school. In ninth grade, I could spell French words perfectly on first hearing. By tenth, I could not. I began preferring Braille over audio for text but lacked the vocabulary to make this preference more than a bratty whim. I started resenting my technology goals, their focus on JAWS?. But most of all, I resented the obsessing over how many friends I did not have. But I was trying to ignore my deafness and be properly, superbly blind as yet another friend/peer gave up repeating themselves, how exasperation hurt worse than enmity and how it was often physi-

cally painful to concentrate in your average high school social milieu.

The coup de gras came during the summer after junior year when I had community O and M lessons. My sense of direction, spatial memory, problem-solving and cane technique were all exemplary. My ability to safely judge traffic flow, sadly, was not. "Hazardously inconsistent," would be too kind, in fact. My O and M instructor did the greatest thing then and got me talking to an audiologist friend of hers. She and I spent days talking about nothing but ears and hearing. The term deafblind did not come up, but I had taken the first crucial steps towards it which was a rational acknowledgement of my hearing loss.

These first steps culminated around October of my senior year, when the coordinator of the then Florida Deafblind project unequivocally identified me as deafblind, to myself and the school system.

I am a sophomore journalism student at Texas Tech now. I have got a dog guide from the Seeing Eye. I have practiced and taught Brazilian JiuJitsu, news casted and interviewed and advocated. In each case, certitude in my deafblind identity has strengthened my self-advocacy crucial to post-secondary success. Stripped of the need to be "just blind," I can acknowledge my limits, and, better assess and communicate my options. My identity is my strength and my community my example.

Zena's

STORY

My name is Zena Docking and I live in Cornwall, England. I was born with sight and hearing impairments. I also have epilepsy and sleep apnoea.

From an early age I became aware of my deafblindness when I used to bump into things more than other children.

People just used to say that I was being clumsy. I remember wanting to tell people that I could not see or hear properly.

When I began primary school people started to understand a little more and this helped me to make some friends.

As a teenager I joined a social group that was for deafblind young people. This made me feel much better about myself and I felt I could achieve a lot more. I gained lots of confidence trying activities like horse riding, ice skating, sailing, rock climbing, surfing and canoeing. My disability did not stop me doing anything.

I am now currently studying for a level one child care course at college. I have already done some voluntary work in a local school. When I have finished my course I would like to work in a nursery. I would really like to work with deafblind children as I know that my own experiences will help me in my work.

It has taken me many years to come to terms with my disability and how it affects me. I feel that I am now getting on with my life; hopefully I can inspire other deafblind young people.







Young Deafblind people live their lives in many different ways. Their choices and decisions are influenced by many things including where they live, their culture and heritage.

Being deafblind in a seeing, hearing world creates challenges. Are these dealt or coped with in different ways in different countries?

This collection of stories provides a unique insight into of how young deafblind people from around the world have succeeded in overcoming the many challenges they have faced.

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