

# MEND NEWS

July 26, 2008



....promoting self-help, not sympathy

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**Dear Supporters,**                      **TWO in A ROW!**

**BBC World** has again selected one of our projects as a finalist of 12 for this year's World Challenge 2008 from 700 project entries sent in from 150 developing countries!                      **This year it is our Kashmir project!**

**If we are to win the \$20,000 first prize we will need to get many more emailed votes sent in this time!**

**So can you rally-the-troops and find some voters who can send in a vote by email?**

**To see details open**

**[www.theworldchallenge.co.uk](http://www.theworldchallenge.co.uk) & click on "She Hope Society"**

**... for those of you sitting round the glowing coals of a woodfire in NZ may like some winter reading ,the submitted BBC outline.**

## **Why was the project initiated and what does it aim to achieve?**

The Hope Society [www.shehope.org](http://www.shehope.org) was set up in 1999 as a registered society to assist disabled and disadvantaged people of Kashmir to live independently and with dignity through rehabilitation programmes involving education, health, mobility, skills' training and employment, small business development supported by a micro-loan scheme, awareness-raising, advocacy, access and human rights.

She Hope continues to establish itself as a transparent, innovative non-government organisation (NGO) that is effectively targeting and uplifting some of the poorest people, particularly those with disabilities, in the remote regions of the Kashmir Valley., where the number of disabled persons in Kashmir grew quickly during the 16 years (1991- 2007) of militancy which caused government medical services and trained personnel to retreat back to the city of Srinagar to avoid exposure to terrorism. Militancy also caused Kashmiris to socially close up and physically avoid seeking help on dangerous, curfewed roads. Although no accurate survey has been carried out to determine the exact number and types of disabled persons in Kashmir it is estimated that about 20,000 people urgently await basic assessment and rehabilitation.

In Kashmir, causes of disability include cerebral palsy, polio, war injuries, accidents, hearing, speech and sight loss, birth deformities, burns, surgical and medical errors and mental problems.

Due to lack of mobility, poverty, low status in the family, and parental apathy, few disabled youths and children attend any school or learn income-generating vocational skills.

**The Hope Disability Centre** was built in 2005-6 and is located beside the Sindh River in Ganderbal, a rural district, 35 kms from Srinagar, the summer capital of Kashmir. The land for the Centre was kindly donated by the manager's family which demonstrated solid commitment to this project and inspired donors from New Zealand and the Middle East to help.

Services are provided at little or no cost to our 450 registered disabled members and include physiotherapy, special needs' education, corrective surgery, fitting of mobility aids such as prostheses, calipers tricycles and wheelchairs, vocational training and micro-credit small business loans, awareness-raising of disability and community-based rehabilitation.

The earthquake of October 2005 also affected Kashmir causing even more disabilities that went untreated in those remote areas near the Pakistan border where Hope has started an outreach project for disabled persons there building on the skills and learning gained at the first Hope Centre. Even Hope Centre too was rocked by that earthquake causing one wall to collapse and all persons in neighbouring Wayil village to sleep outside their homes for a week following more tremors!!

1 July 2008



**WORLD CHALLENGE 08**

In association with 

## 12 Finalists

### *The 12 finalists have been chosen!*

Following an overwhelming response for nominations for World Challenge 08, we are delighted to announce that the 12 finalists have now been chosen. To view the projects chosen please [click here](#).

We received over 700 nominations from around the world and the judging panel were extremely impressed by the quality and diversity of nominations received. Choosing the 12 finalists proved enormously difficult and we would like to thank everyone who took the time to enter World Challenge 08. Congratulations to the 12 finalists.

Details on how you can vote for your favourite will be released soon. The lucky winner of World Challenge 08 will receive a grant of US\$20,000 to invest and help develop their project even further and two runners up will receive grants of \$10,000 each. Projects can be entered under six different categories, community welfare & enterprise, health & education, sustainable farming, energy, water, and environment.

For more information about World Challenge 08, visit [theworldchallenge.co.uk](http://theworldchallenge.co.uk).

Regards  
The World Challenge Team

The BBC has a new policy on competitions.  
Visit [bbc.com/competitioncode](http://bbc.com/competitioncode)

### **OUTLINE: She Hope Society**

India

The She Hope society has the motto "self help, not sympathy" and aims to help the disadvantaged of Kashmir live independently and with dignity. Rehabilitated through education and micro loans, as well as physiotherapy and corrective surgery, the She Hope Society estimates that 20,000 disabled Kashmiris could benefit.

### Find Out More

Find out more about World Challenge 08 and have your say online.

[Launch website](#)



“ We are trying to make something beautiful, and useful, in an active theatre of war. ”

~ Sarah Chayes ~  
Arghand, AFGHANISTAN



Newsweek

2. **How does the project measure its achievements**

Hope Centre is breathing new life, opportunity and choice into many young Kashmiri lives whose disabilities had left them stranded at home, with no future, and little mobility, independence or dignity. Empowering each disabled person frees up a family member to do other things. Fitting of mobility aids opens up the joy of movement and sound and exercise!

The growing list of disabled children, youth and adults who have received help from Hope highlights its achievements. This is coupled with the increasing number of parents and caregivers who see the benefits of rehabilitation and are rallying in support of Hope Centre. Even the once-feared Army, and Jammu-Kashmir Police are now supporting Hope services by funding the school bus, its hydro-electric power plant and even surgery costs.

The government Social Welfare Department regularly checks progress at Hope to see how it can set up similar, small efficient and active disability centres. Local doctors and dentists volunteer their services now on visits to Hope with free checkups and assessments. Compassion and community support is slowly returning to Kashmir after a long absence!

### **3. How does this project benefit the community?**

With 54% of the population still illiterate in rural Kashmir general awareness that disability can be addressed, challenged and overcome is still low in Kashmir.

There is only one main government centre for disability services. But getting quality care there for Hope members has proven costly in time and travel expenses and requiring much patience.

In just two years Hope Centre has developed most disability support services including testing the deaf for hearing levels and fitting of donated hearing aids. And recently Hope opened a blood testing unit while still arranging corrective surgery and followup physiotherapy so that patients can walk.

**Hope Centre** has quickly established itself as a role-model for the rest of Kashmir.

A big part of the task is changing perceptions of many Kashmiris through awareness-raising as they have not valued disabled family members when they are not able to carry out farm tasks or do manual work like carrying loads. While wealthy Kashmiris often will not spend money on quality rehabilitation services they will "spoil" their children with clothes and attention. But unfortunately, instead of offering their disabled members "self-help", they give "sympathy"!

And physiotherapists know that quality rehabilitation requires specific and regular routine where "**no pain, no gain!**"

So this project is for both the disabled beneficiary and their caregivers who are changing their attitudes so they actively assist the process of rehabilitation.

It is important for parents to see the often, imperceptibly-slow but permanent changes to the mobility, health and special education levels of their disabled family members at the Hope Centre and to see what is possible with rehabilitation, mobility, skills training and caring staff.

Hope is bravely challenging the whole needs of disabled persons in that tough, cold Himalayan country that lies isolated during cold winters that get down to -20 C!

### **4. How does the project use environmental resources sustainably?**

**WATER:** When the mountain ice has melted in summer Hope Centre uses irrigation canal water to power its hydro-electric unit giving 24 hour power. This has overcome the chronic power cuts that all of Kashmir is subjected to even though this land produces much of India's power.

**RECYCLING:** Hope Centre recycles hearing aids from New Zealand and Europe which reduces costs greatly for deaf persons who come from very poor, and often feudal villages.

As for recycling plastic bottles Hope Centre has demonstrated that simple prosthetic arms can be fitted to amputees who have lost arms by using "sawn-off" plastic drink bottles. One man who lost both arms from electrocution was fitted with simple bottle prostheses into which are screwed the caps holding his tools such as spoon, knife and fork, so that he was able to feed himself for first time in 10 years!!

With the help of a NZ organisation MEND Hope Centre has been developing low-cost, quality tools and ball joint at arm so that better coordination and function of tools are achieved. And a set of tools costs only \$10 to fit!

Also the development of low-cost tricycles at Hope Centre that use recycled bicycle parts and inner tube for seats show that for as little as \$50, quality, rough terrain, hand-powered mobility aids can be made locally that are appropriate technology for local conditions. Not solutions imposed from outside!

**FOOD:** A fish pond is under construction at Hope to produce quality carp that will feed the special school students and also produce fish for sale to the public to raise funds for the centre's operations.

**CONSTRUCTION:** The Hope Centre was built all by hand using local river stones and bricks made in the district. The windows were made from local wood hand-hewn in nearby village. Hand and foot sewing machines power the centre's sewing classes.

**CRAFTS:** Products for sale, such as willow baskets are made by Hope Centre members using local materials

### **5. Why will this project win WC2008?**

*In this remote, enchanting, ( 98%) muslim Himalayan valley of Kashmir, invaded and colonised for centuries from the Mughals to the British, yet now finally released from militancy and turmoil, the Hope Centre is a beacon of light for many once-neglected disabled persons.*

*Hope's young, caring manager Sami Wani, a physiotherapist, and his small staff, have shown how the long roadmap to walking and usefulness can be achieved by disabled persons there through a rigorous, often painful, programme involving accurate diagnosis, corrective surgery, physiotherapy and fitting of quality mobility aids causing life-changing intervention.*

*This project in remote Kashmir will inspire BBC World viewers and those organisations in developing countries to model their own disability services on the Hope Centre model.*

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## **Nepal**

***We are planning to help a group of disabled persons make a TV series about disability that will screen on Nepal's government TV station in 2008-9.***

***One of the producers, Tikaram Dhungana , has muscular dystrophy. Here he tells his story!***

### **My childhood**

I was born in a poor family in a remote village Salyan in Solukhumbu district (a gate way to Mt.Everest) in 1977. There were seven members-father, mother, two brothers, two sisters and myself. I was the middle son. My parents were uneducated and had to live on the small income they made from working in other's farms. We could hardly sustain. When my parents died, then I was overlooked in the family. I was suffering from Duchenne Muscular Dystrophy (MD).



People in the village are uneducated and don't know about this disease. They used to torment me and curse me for my disease. I was deprived of all my fundamental rights- the right to education; right to play and learn, right to participate in social activities etc. I still remember the ordeals I had to go through in my childhood.

The children, affected by such disease, are not admitted to schools on account of their inability to control urine and shit. Though they are admitted to schools, they are hated in the classrooms and are not well cared either. This is the main reason why I was thwarted from getting education.

### **DEFINITION**

*Muscular dystrophy (MD) is the name for a group of disorders in which muscle size and strength gradually decrease over time. Nine different forms of the disorder have been discovered.*

***Duchenne Muscular Dystrophy (DMD).*** DMD primarily affects young boys. It causes weakness in the muscles that gets worse over time. The problem usually begins in the legs and then spreads to muscles in other parts of the body. It is the severest form of MD. DMD occurs in about 1 out of every 3,500 male births. About 8,000 boys and young men in the United States have the disorder. A milder form of the disorder occurs in a very few females.

### **CAUSES**

*Wasting of muscle tissue causes all forms of muscular dystrophy. Muscle cells die, and muscles become weaker and unable to perform their normal functions. Researchers are still uncertain how this loss of muscle function takes place. They believe that cells may lose their ability to produce certain muscle proteins. Proteins are essential chemicals that occur in all cells and have many different functions. For example, they act as building blocks for cells and as enzymes. Enzymes are special kinds of proteins that control the rate at which chemical reactions take place in cells.*

Researchers believe that some forms of MD occur because some muscle proteins are absent or present in smaller-than-average amounts. In such cases, muscle tissue becomes weak. Other muscle proteins may be needed to repair damage in muscle tissue. If those proteins are absent, muscles that are damaged cannot be repaired. In most cases, the connection between absent muscle proteins or reduced amounts of proteins and various forms of MD is simply not yet known.

### **DMD Symptoms**

The first symptoms of DMD appear during preschool years. The disorder affects the legs first. A boy has trouble walking and maintaining balance. In most cases, he begins walking three to six months later than average. As his calf muscles begin to weaken, he may change the way he walks. He places his legs farther apart in order to maintain balance. Walking this way produces a waddling effect that is characteristic of DMD.

Contractures usually begin at about the age of five or six. They affect the calf muscles most severely, pulling the foot down and back. This forces a boy to walk on his tiptoes. Balance becomes more of a problem. As a result, falls and broken bones become common at this age. By the age of nine or ten, a boy with DMD might not be able to climb stairs or stand by himself. Most DMD patients have to use a wheelchair by the age of twelve.



### **FAULTY GENES AND MD**

Sometimes faulty genes occur on the Y chromosome but not the X chromosome. Chromosomes are structures in cells that contain many genes. Women have two X chromosomes and no Y chromosomes. Men have one X chromosome and one Y chromosome. Faulty genes that occur in Y-chromosomes are only present in men. This explains why some forms of muscular dystrophy affect men only. Men inherit those faulty genes, but women do not.

Muscles in other parts of the body are also weakened. When muscles in the upper body are affected, scoliosis (see scoliosis entry), or curvature of the spine, may result. The most serious problem, however, affects the muscles of the diaphragm. The diaphragm provides the in-and-out force that allows a person to breathe and to cough. As the diaphragm weakens, breathing becomes more difficult and patients will have less energy and stamina. They also become more subject to infection because they cannot cough up infectious agents that get into their lungs. Young men with DMD can live into their twenties provided they have mechanical aids to help with their breathing and good respiratory (breathing system) hygiene. About a third of the boys with DMD also have learning disorders. These disorders can include problems with learning by ear and trouble paying attention to some tasks. Specialized educational programs can help compensate for these disorders.

### **TREATMENT**

There are currently no cures for any form of muscular dystrophy. A few drugs have been found that slow the progress of some forms of MD. For example, prednisone, a corticosteroid, slows the progress of DMD. Generally speaking, however, drugs have a limited and uncertain value in the treatment of MD. The primary goal of treatment programs for MD is to prevent complications. The major complications are decreased ability to move on one's own, contractures, scoliosis, heart defects, and respiratory problems.

### **MY AIM**

Though I am suffering from incurable disease DMD, I will do something worthy which will benefit the underprivileged group. I can't perform my daily activities without the support of other people. I can't go to toilet on my own. I thought that I would be good-for-nothing in the past. But I met a group of disabled and handicapped friends who have inspired me to live a meaningful life in spite of the disability. So, I have been making a film called "SITA" to educate people and create public awareness against blind

*faith, superstitions, untouchability, and other dead habits that still exist in the society. I am going to launch this film soon. I like reading newspapers and literary books.*

*Realizing the plights of the disabled and helpless people, I am strongly determined to help the disabled and helpless children/ people to get education, nutrition, proper health care and protection thinking that they may be enabled to lead a life of dignity in the society. If we can get funding for the proposed series it will give a highly committed disabled some positive work and aims for 2008 –9 and help us create awareness for the disabled sector.*

*I have also set up a non political, non profitable and non governmental organization which chiefly aims:*

- 1. To provide free education to the disabled children whose body from the waist to the feet can't function and who are confined to the wheel chair.*
- 2. To provide them free food, clothes, medicines and hostel facilities.*
- 3. To protect there fundamental human rights.*
- 4. To provide job oriented trainings to the adult disabled*
- 5. To enable and empower them to improve their living standard*

**My APPEAL** *No man knows what he can do until he tries. So, I don't let myself die until my heart stops. We, disabled people have also inherent potentials within us waiting to blossom. We don't need your sympathy but long for equal opportunities to discover and reach our potential. We have to show that we can also bring changes in the society. If we get equality for education and skills development, we can undoubtedly contribute to the welfare of the mankind and the country.*

Please contact me : Tika Ram Dhungana [ramtika@yahoo.co.uk](mailto:ramtika@yahoo.co.uk)

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***THANKYOU to all the Hearing Associations in NZ and others who have kindly sent us hearing aids. These are now being fitted to deaf persons here in Nepal and Kashmir!***

***AND THANKYOU TO ALL YOU DONORS WHO CONTINUE TO KEEP MEND' s PROJECTS GOING and GROWING!***

*Quote: ...“if you find a path with no obstacles... it probably doesn't lead anywhere”*

***Diane Emerson (Treasurer)***  
***Baker (Secretary)***

***Peter***

***Rob Buchanan (Director)***



