## **URGENT APPEAL**

## Kidney disease deaths in remote Odisha

**Integrated Village Development Trust** works in remote rural areas in Odisha, India, helping impoverished communities to improve their circumstances and build a better life for themselves and their families. Six years ago we encountered a totally unexpected problem. In Thakapali (pop. 500) there had recently been ten deaths due to kidney disease. The cause was unknown. But it was a shocking revelation. Most of the deaths were adult males, the main breadwinners for their families, so the loss was doubly serious. In this remote area medical help is hard to reach and the cost of treatment is beyond the reach of most people. There is no cure.

After a vigorous campaign a government medical team was sent to the village to investigate, but in spite of repeated requests they failed to make their report public, and no government action has been taken.

We carried out our own survey within 67 project villages in Nuapada District; 12 of them had alarming rates of kidney disease with many fatalities. This is not the normal kidney disease which we see in the west, and its cause remains a mystery. Over several years we explored possibilites, looking at any possible correlation with tribal or caste group, or with another disease such as malaria, diabetes, sickle cell anaemia, or fluorosis (all of which are common in the area and have an impact on kidney health).



"We have this other problem – our men keep dying of kidney disease." A women's quiet voice broke the news to us at a village meeting in Thakapali; we knew right away that it was important.

We made little progress - and then there was a sudden breakthrough.

A similar situation has been noticed in other parts of the world, and there are parallels – extreme poverty, hard manual work in high temperatures and the misuse of agrochemicals. Research is being done in some of these places, especially in Central America, Sri Lanka, and, to our surprise, in India too. Our contact with these other groups has helped bring together people from all over the world. We have taken on the responsibility for coordinating information in India, liaising with groups elsewhere in the world. We are now part of the process that will help solve this problem, bringing relief to villagers in our project area. Overleaf say how we will do that.

Dinesh lost his son to kidney disease, and has now contracted the disease himself.



If you would like to know more about this particular issue, please contact: Helena Nightingale at 01872 270954, 7a Rosewin Row, TRURO, Cornwall TR1 1HG or helenanightingle@hotmail.com

And if you would like to know about our other work, please ask Helena or visit www.ivdtrust.org

Integrated Village Development Trust (Charity No. 1013316), 39 St. John Street, OXFORD OX1 2LH

As a result of all our enquiries and discussions with those dealing with this problem elsewhere, we have organised for an international medical research team to visit the villages in our project area to explore the situation. This team will include people from the London School of Hygiene and Tropical Medicine and the University of Lund who will carry out biopsies to identify the disease and give us and local health-workers valuable medical advice. They will be visiting our project in January, 2016, and will be accompanied by an experienced campaign team who will help us set up our own campaign and provide valuable resources and training materials which can be used when they have left. This (Phase 1) will set the groundwork for a longer project (Phase 2) which we will manage in our usual way: working with local trained volunteers to establish precisely how serious the problem is in our area, to inform people how they can reduce their risk of contracting the disease, to help with treatment to slow down the progress of the disease (there is no cure), and to campaign for the government to carry out their responsibilities and take action to provide proper support for the affected. A special feature of our plan is to use as volunteers young people who have completed school and/or college education and who are currently under-employed in their villages. The training and experience that we provide will stand them in good stead for the future.

The total cost of both phases of the project will be  $\pounds70,224$ . Of this, Phase 1 will cost  $\pounds13,544$ . This will set the foundation for Phase 2 which will cost  $\pounds56,680$ . We are submitting funding applications for Phase 2 in the usual way, but we need the money for Phase 1 urgently so that we can provide the necessary support to the visiting medical and campaign teams early in January 2016.

## Can you please help us raise the £13,544 needed for Phase 1?

We believe all our work brings important and valuable change to the people we work with. However, the first minute that we heard of this story, we knew that we had no choice but to do something to help solve the problem. It has taken many years to make this progress, years in which many have died leaving unsupported families. Many more have contracted the disease, and communities continue to live in fear that they or someone in their family will be next. We can't cure this disease, but we can help prevent it and make lives better for those who are affected. And we can also contribute to international medical understanding as we do this work.

Please do help us in any way you can. Donations of any size will be warmly welcomed, and, on behalf of the villagers in Thakapali and elsewhere, we thank you very much.

Ways of making a donation:

**By cheque**: Made out to "IVDT" and sent to Mike Wright, 39 St. John Street, OXFORD OX1 2LH

**By bank payment**: to 'IVDT', Acc. No. 87213508, Sort Code 54-21-23, Nat. West. Bank, Cornmarket Street, Oxford OX1 3ES

By Paypal: through our website link - see www.ivdtrust.org

Please remember to let us know that you have made a donation so we can thank you, and also to let us know if you would like us to claim back the tax you have paid on your donation which will give us an extra 23p for every £1 you donate.

## THANK YOU EVERYONE for your SUPPORT