

Fighting Fluorosis in Assam

Renewal and Recovery made possible by Government and Civil Society



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FLUORIDE KNOWLEDGE AND ACTION NETWORK

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Background

Assam Fluorosis: some facts	
First Detected in Assam	1999, Teklanjung village Karbianglong, Assam
No of Districts highly affected	7
Population estimated as affected	More than 6 lakh people with manifestations of Skeletal and Dental fluorosis

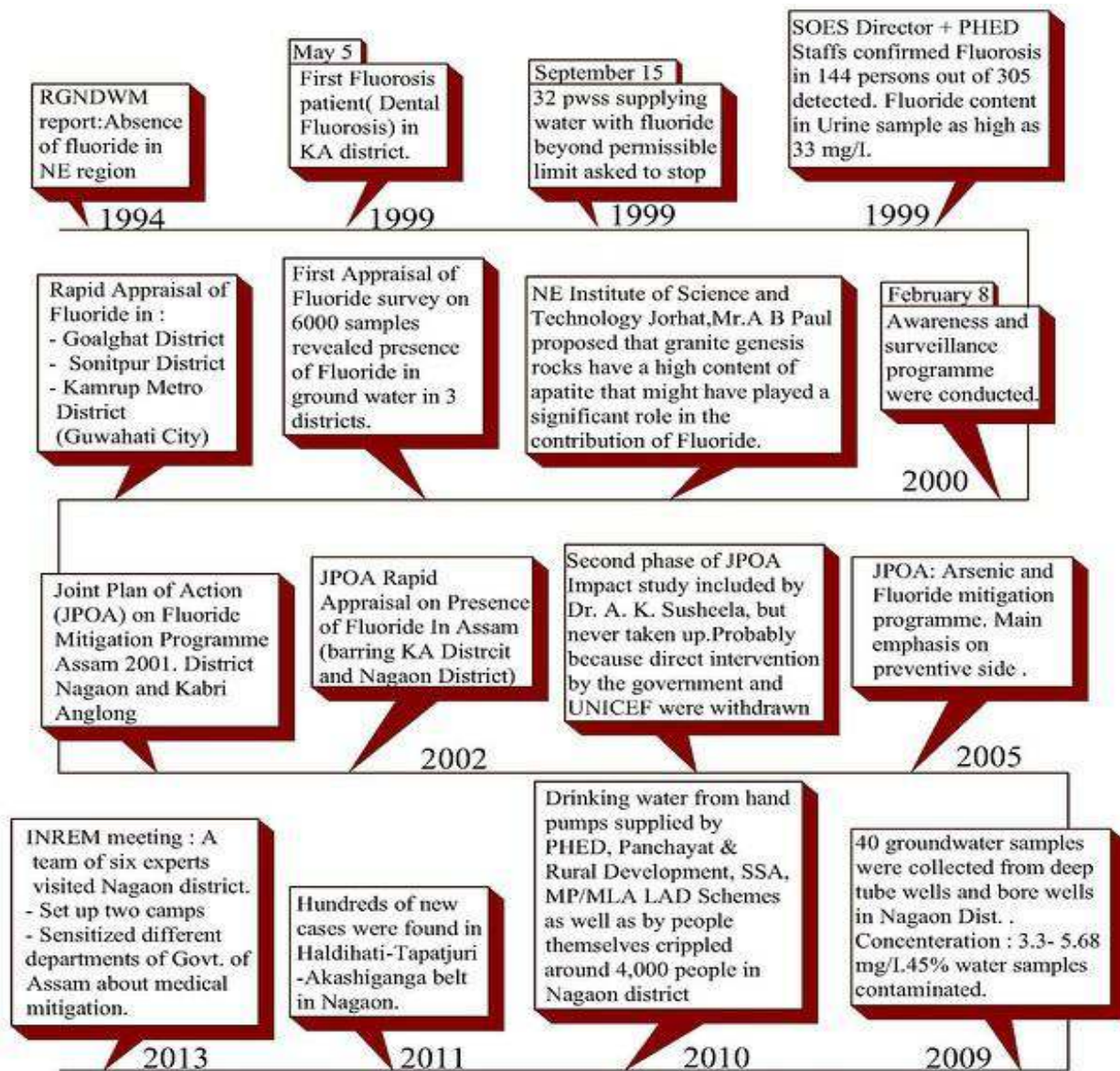
The first case of Dental Fluorosis in Assam was discovered in 1999 in Teklanjung village in Karbi Anglong District in June 1999. After this fluoride in groundwater sources was tested and was found to be around 23.4 ppm in some water sources (Ramsapathar) of this area.

Initially, when the problem of fluorosis was discovered, there was reluctance to accept it from people and society at large, including the government departments and civil society. Studies later on in November, 1999 by the Central Groundwater Board (CGWB) confirmed the presence of fluoride in Assam and paved the way for UNICEF and the government to come together to collaborate for Fluoride mitigation. The Addl. Chief Engineer of PHE in Assam, Mr A B Paul played a significant role in identification and recognition of Fluoride in Assam, and later in developing and implementing an action plan to help mitigate the problem.

A Joint plan of action (JPOA) emerged between UNICEF and Government of Assam (PHED) in technical collaboration with Fluorosis Research and Rural Development Foundation (FRRDF) as a first step. This steered a study forward to understand the impact of fluorosis in Assam. This study was undertaken in Karbi Anglong and Nagaon districts and unearthed thousands of fluorosis patients, with some crippled for life.

As part of the Joint Plan of Action (JPOA) in Nagaon , a health screening of school children and people in endemic areas was performed. Food habits, source of drinking water and fluoride content data were collected. Awareness generation campaigns were organised. IEC material was prepared and distributed. Taking clue from what was found, a rapid appraisal then took place in the districts other than Karbianglong and Nagaon.

Fig A- A sequence of events on Fluorosis mitigation efforts in Assam since 1994^{1,3}



From 2013-14, about 9 districts: Barpeta, Dhubri, Goalpara, Golaghat, Jorhat, Kamrup, Karbi Anglong, Karimganj and Nagaon were identified. In 2014-15, this number jumped to 19 and new inclusions were Baska, Cachar, Chirang, Darrang, Dibrugar, Morigaon, Nalbari, Sibsagar, Sonitpur, Udalguri). In 2015-16 this number has jumped to 22 districts with new inclusions of Bongaigaon, Lakhimpur and Tinsukia. Within the past 2 years High Fluoride in privately owned tubewells in Guwahati is also being reported by people and this has become a cause for concern. Please see Figure B for an entire Fluoride map of Assam which has been developed using the national NWRDP Database. As of April, 2016, now these numbers stand at 11 districts, 24 blocks, 793 Habitations, population at risk 3.9 million (rural)+ 0.6 million (Guwahati City) after proper scrutiny by PHED.

There is an evident need felt therefore in government circles especially the PHE, WSSO and Health Departments to quickly understand this tricky problem and find means for dealing with it in places that have been affected.

Fig B- The Fluoride affected districts of Assam as reported using NWRDP Data. For entire interactive Map up to habitation level, please see <http://www.easymapmaker.com/map/c2a28383f7e7aa2cfd2c326cf2d87e31>



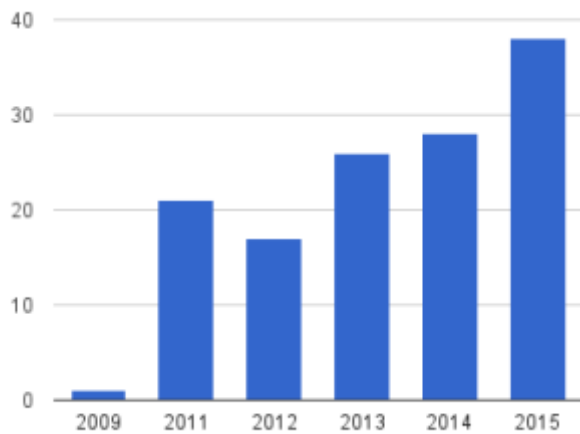
The Fluoride Knowledge and Action Network's involvement in Assam

The Fluoride Knowledge and Action Network (FKAN) with the support of Arghyam, a philanthropic organization working for Safe water and sanitation, got involved in Assam through a combined expert team visit in 2013 on invitation from the Water and Sanitation Support organisation (WSSO) of the Government of Assam, and on facilitation by Mr A B Paul, who had by then retired from the PHE as the Chief Engineer of Assam state. The team, that included eminent specialists such as Dr Raja Reddy and Ms Suneetha Sapur, tried to understand field realities in Assam on fluorosis through a field visit to two villages. It interacted with government department like PHED, WSSO and NRHM and shared its observations and recommendations based on what it had found with the government. The focus on Assam, early on for the FKAN was mainly due to the efforts of Mr Ayan Biswas of Arghyam, who felt that a focus on Assam Safe water issues is much needed. As Dr Raja Reddy expressed in anguish after this visit, “ ...

These are one of the worst Skeletal Fluorosis cases I have ever seen ...". Coming from a eminent Neurosurgeon who has spent more than 40 years working on this disease, this reflected for everybody the seriousness of the problem in Akashiganga and Tapatjuri areas of Hojai division, Nagaon.

The visit helped provide recognition to FKAN as a serious entity focusing on the fluoride issue in the state². Starting from this, network started consulting with a range of stakeholders which included researchers, Academia, NGO's and people from all walks of life at large. The network realized that

Fig-C An impact analysis of the campaign which shows the coverage on Fluorosis in prominent English News Media such as Assam Tribune before and after the network got involved (number of English media news articles on Fluoride issue every year)



first there is need to bring out more understanding and awareness among educated and informed people of the society to recognize and understand the problem. A one year campaign "United for Assam United for Water" was started following this, which was able to garner interest and was reported widely in the press and media.

As can be observed here, before the network came into picture the media reporting on Fluoride issues in Assam had been pretty sporadic, after the network's involvement in 2013 it has started consistently increasing each year. To be noted is that in this period, there have been two editorials of the Assam Tribune that have acknowledged the role of FKAN in bringing the Fluorosis issue to light in Assam.

This engagement at different levels culminated in a focussed civil society consultation taking place on the 19th of November which gave shape to two significant developments; a State water quality and health resource centre on water quality and a field intervention centre.

The State Water quality and health resource Centre (WQHRC) rechristened later as SWaCHA (Safe Water centre for Health Assam) has been able to be a space for all those wanting to act on issues related to water quality in Assam and has been able to bind people on the serious issue of Fluorosis as a collective front. The Fluoride mitigation support centre in Nagaon on the other hand has been path breaking since its inception in showing examples to the government of mitigating Fluorosis through a Safe water and Nutrition based approach.

The Fluoride Mitigation Support Centre of Nagaon

Since its inception the Fluoride Mitigation and Support Centre (FMSC)⁴ has been working with the concept that Safe Water and Good Nutrition can help improve the Skeletal Fluorosis situation in children. 6 villages including Tapatjuri in Haldihati area under Akashiganga GP within the Hojai Division were identified as a highly affected areas and the FMSC helped converge the activities of both the PHE and Health departments to help the affected people. The initial plight of these

children of Tapatjuri (more than 400 such children here) was identified, documented through painstaking field works of Dharani Saikia of ECC Namrup, A.B.Paul, Akashiganga Youth Club over a long period and documented and propagated by Er. Paul and Dharani Saikia through series of reporting and presentations. Later Mr Nilutpal Das of EcoConcept produced the film, “The Tale of Tapatjuri” <https://www.youtube.com/watch?v=nSrrwGfrPVw>. The EcoConcept has also produced an excellent basic film on the Fluoride issue called “Know Fluoride, Prevent Fluorosis (<https://www.youtube.com/watch?v=u2sv9e3bL6Q>)

This concept of converging Safe water and Nutrition for Fluorosis mitigation was developed through the work of INREM Foundation in Jhabua (MP) through a research based focused intervention with 25 children in 2010 and later with several thousand children now⁹. The remarkable results from Jhabua inspired the possibility of such work in Nagaon, Assam, and was guided by Dr Raja Reddy after his visit in 2010.

The Safe Water-Good Nutrition approach was tried first in a group of 20 children in Tapatjuri and a combination of nutritional supplement tablets (Calcium, Magnesium supplements and Vitamin C through food) and Safe water were provided to these children. It must be noted here that the local administration provided extensive support in this entire effort by improving the Water supply schemes locally upon advise of the network team and consistent work of local people based monitoring lead by Mr Dharani Saikia, a local activist who has coordinated the FMSC activities of Nagaon. This has also been supported well by Mr Ashoke Das, PHED Secretary, Govt of Assam.

The progress these children made was monitored over a period of one year and can be seen from the pictures here, dramatic changes in children were observed, all with trying out just safe water and better nutritional supplements. Bone deformities that were earlier thought to be destined for being crippled for life, have recovered thanks to this innovative approach. Also urinary fluoride has been observed to be reduced significantly. Dr.Rubi Kotoky , Regional Dental Medical College, Dr. Anjila Paul (PGT-Surgery, Guwahati Medical College checked the patients in the field and supported FMSC as volunteers. Some community women leaders such as Mehbooba Begum was involved in IEC supportive role. Some community women leaders such as Mehbooba Begum played a key and significant role in this recovery process. The Fig D shows the visual recovery of 2 such children and their respective stories. Also the Appendix gives information on how Urinary fluoride has reduced significantly over this period. Within this process, the support given by Dr Arundhati Deka, State head of the National Programme of Prevention and Control of Fluorosis (NPPCF) in Assam was crucial. The local public health department helped with free X-rays and urinary fluoride tests that were critical in diagnosing and monitoring the children’s health.

Many more children are now being helped by the FMSC and the results that are coming out are changing the perception of all stakeholders including the community, government and civil society that Fluorosis can be tackled with a very simple, community based approach. The FMSC has also been pivotal in acting as a quick interface between the community and the government departments and this has helped these departments to take note of the problems arising out of unsafe water and respond to them. It has also prompted the PHED and Health Departments to feel the need for more such centres to come up elsewhere in the State. It has also given reason for the group working in Assam to try and push for this model of work.

Fig D: Skeletal Fluorosis affected children showing significant improvements since 2015



The Story of Furhan and Sabina

Farhan Uddin was 5 years old in 2013 suffering from skeletal fluorosis. He had problems of pains in leg and knee, bent leg, and trouble walking with constant fatigue. His parent thought that the causes was lengra bhut (ghost) and spent more than Rs. 20,000 for village doctor called Bej. Drinking water source was hand pump containing 10 mg/l of fluoride. 60 mg/l fluoride found in urine. His family was advised to drink water from close to pond after boiling. The Dikharumukh pipewater scheme also improved the water situation. He was provided Calcium and Magnesium tablets regularly by the FMSC. Amla pickles were given regularly. By 2015, he has recovered with legs straightening, Urinary fluoride dropping from 60 mg/l to 1 mg/l and he can walk properly with good energy. Farhan has become a hope for other children of Tapatjuri.



Sabina was 5 years old child in 2013, suffering from dental and skeletal fluorosis. Her grandfather Ata Akbar was having a joint family of 15 members. They are poor daily wage labourers. She had bent legs, with pain in legs and knee. The drinking water source was hand pump containing 10 mg/l of fluoride and 52 mg/l fluoride found in urine. She was provided with an improved Water supply scheme of Dikharumukh, along with Calcium and Magnesium supplements and Amla pickle. Within 2 years, hers legs started straightening. Her urinary fluoride dropped from 52 mg/l to 1.2 mg/l. However, her father died during this period, but her family faithfully continues to help her recover from Fluorosis.

Furhan and Sabina are two of the many children who are part of the FMSC's Fluorosis recovery programme. They are showing light to the many more affected from this disease and helping give all of us hope that we can tackle this problem.

Wider Acceptance by Government and by Respected International Media	Other Significant Activities of the Network in Assam
<ul style="list-style-type: none"> • Dharani Saikia a key person at the Fluorosis Mitigation Support Centre has been taken in the State Water Quality Task Force • The Guardian Newspaper of UK published an article about the recovery of the children of Tapatjuri (https://www.theguardian.com/global-development-professionals-network/2015/oct/29/the-indian-village-fighting-fluoride-poisoning-with-vitamins-and-cleanwater). A Journalist Joshua Carroll did an excellent investigative story about this remarkable work of Nagaon by Mr A B Paul and Mr Dharini Saikia • PHED has committed one Ion meter and Spectrophotometer for Fluoride and all other chemicals found in water, including fluoride in urine, for FMSC • The Forest Department is supporting the FMSC in growing a varieties of saplings in Nagaon that have foods growing with high nutrients to combat Fluorosis • The secretary, PHED has instructed to make Two Block level consultants available to support the mitigation effort through FMSC in Nagaon 	<ul style="list-style-type: none"> • State water quality resource centre meeting in March 2015 • Fluorosis training for Government Doctors by Dr Raja Reddy, 2015 • Study of the Water quality resource centre by IRMA student, Jyotismita Devi⁵ • Study of Public health Fluorosis programme at FMSC Nagaon by Ms Mousumi Sinha • Dental Fluorosis camps facilitated by Dr Ruby Kotoky, Guwahati Medical Research Hospital • Inter- departmental PHE, Health , Forest , education and PHED departments in Nagao

What do we learn from our experiences in Assam

Engaging in Assam is a classic example of an immense desire to make a difference being present in the government but a lack of information to proceed with and a need for expert capacity

Safe Water

- The bare bandwidth of sources to monitor and in remoteness of hilly areas makes it almost impossible to carry out regular monitoring. There is a need for civil society groups people from within the community to actively report from on field so that government departments that are responsible is able to take corrective action where and when necessary. This needs information about water sources
- Supply of water is erratic and uneven with very few people in charge of huge areas under their jurisdiction. User committees could help this problem and need to be encouraged made use of better.
- There is a critical need for real time data assessment and monitoring, a need for PHED to share the point source data information available with them with people
- With it's diverse topography, it would be useful to match contaminants found in different regions of Assam with the best suited local options.

Food and Nutrition

- Supplementing minerals like Calcium, Magnesium has been found to be useful in Improving the Fluorosis affected, in some cases showing direct examples of improvement through the FMSC experiment in Tapatjuri
- Food that is found to have sufficient quantities of these minerals need to be promoted in Assam
- Mid Day meal programs in Assam and the ICDS program need to be modified so these elements in food can be accommodated

Medical Relief and Rehabilitation

The highly Skeletal fluorosis affected people of Assam need urgent attention.

- A system needs to be in place that could cater to referring such Skeletal fluorosis cases to Medical Facilities for further examination and treatment
- Proper rehabilitation plans need to be developed for the fluorosis affected in Assam so that chances of recovery and after care are improved
- In some cases, after extreme care, corrective surgeries need to be performed. But this requires the attention of highly specialized surgeons, hence should not be attempted very casually without precaution

Institutional Development and Sustainability

- Departments at the moment are not quite aware about how they need to relate with each another in execution of mitigation plans for Fluorosis. A lack of an “on paper understanding” or an institutional mechanism in dealing with the problem is making it difficult for them to decipher roles
- Coordination between relevant departments that have a relevance in mitigating the problem is critical
- There is a need for departments to assess their roles and see how they can together, the assessment needs to be taking place at all levels
- Capacity building at the lowest levels where programs are executed i.e. Public health centres, community health workers, ASHA workers, PHED engineers needs to take place
- The FMSC and the State JPOA have shown an example by which the Fluoride problem of Assam can be tackled through the active participation of Communities and Government Departments

Future plans: The Joint Plan of Action with Government of Assam through the SWaCHA

The FKAN is now on the verge of implementing a Joint plan of action (JPOA) with the government in Assam through the Safe Water Centre for Healthy Assam (SWaCHA), which is an attempt to look at the State wide water quality problem at one place. This is being taken ahead along with multiple stakeholders on the entire Safe water and Health issues. Along with the FKAN, the Arsenic Knowledge and Action Network (AKAN) is also involved in the development of SWaCHA.

The SWaCHA is entrusted with the task of

- Assisting the Government in identifying important problem areas
- Help strategic thinking on problem solving with research and pilots
- Partner with Government agencies on making programmes achieve their potential
- Brings together different government and other agencies together on one platform

The SWaCHA will in this next year

- Develop other field mitigation support centres on the lines of FMSC Tapatjuri and have state level coordination across departments
- Test and strengthen Behavior change Communication of Departments and Community and help Government execute it in few districts
- Determining the Disease Burden of Fluorosis through health surveys in partnership with the Government

The Hope for Assam's Children



The beginning of Hope has been seeded. The Tapatjuri experience shows us that it is possible to bring smiles to the faces of these children. We all wish that the SWaCHA centre helps us to work with the Government of Assam and goes towards achieving this all across Assam.

References

1. A situational Analysis of Assam by the People in Centre group, Ahmedabad
2. Fluoride Mitigation Support Centre, Tapatjuri, Nagaon: A Context by Retd Chief Engineer PHED, A.B Paul
3. A timeline of activities on Fluorosis by Mukta Ramola from the People in Centre group
4. A report on the Fluoride Mitigation Support Centre activities by Shri Dharani Saikia, Fluoride Mitigation Support Centre
5. Assam State Water quality and Health Resource Centre, An IRMA Development Internship Study by Jyotismita Devi
6. A Public Health Clinic (PHC) level model for Fluorosis mitigation, A Study by Mousumi Sinha
7. Know Fluoride, Know Fluorosis, A film by Nilutpal Das, EcoConcepts
8. The Tale of Tapatjuri, A film by Nilutpal Das, EcoConcepts
9. Jhabua Model of Fluorosis Mitigation, INREM Foundation, 2013
10. Recovery of Furhan and Sabina, Case Studies by Dharani Saikia

Key Persons

Mr AB Paul, Retired chief Executive Engineer, Assam

Mr Nilutpal Das, Eco Concepts

Mr Nripendra Sharma, PHE

Mr Dharani Saikia, FMSC Nagaon

Ms. Arundhati Deka, State programme head, National Programme for Prevention and Mitigation of Fluorosis (NPPCF), Assam

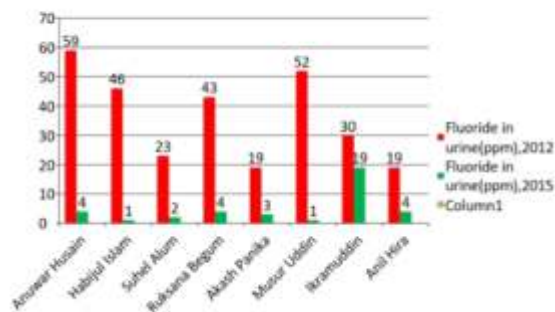
Mr Partha Jyoti Das, Aaranyak

Partho Patwari, Centre for Microfinance and Livelihoods

Abhinandan Saikia, TISS

Ruby Kotoky, Guwahati Medical Research Hospita

Fluoride level decrease in urine



Appendix

The improvements in Fluorosis in children can be measured through Urinary fluoride levels. The safety limit for Urinary fluoride is 1 mg/l and it can be seen that this level is slowly getting reached for the children gradually. One can attribute this fall in Urinary fluoride mainly to the FMSC intervention of Safe water and Good nutrition. However, this data by itself cannot rule out external factors that could also have played a role in this decrease.

@fluorideindia on twitter

Facebook group fluorideindia

@fluorideindia on Medium

About Fluoride Knowledge and Action Network (FKAN)

The Fluoride Knowledge and Action Network (www.fluorideindia.org) is a nationwide body formed in 2013 with an objective of bringing solutions to Fluoride affected people across India. The FKAN was initiated by Arghyam, a philanthropic trust based in Bangalore and is coordinated by INREM Foundation, an Anand, Gujarat based organization working on Water quality and Health issues.

Within the few years of its existence, the FKAN has grown towards a unique network consisting of the prime experts of the Fluoride issue, main institutions within the Government that are mandated to deliver the solutions, and important civil society groups which are innovating on new ideas.

In few states such as Assam, Telangana, Madhya Pradesh, Karnataka and Andhra Pradesh, the network has been able to develop working models of mitigation efforts, both as community based programmes, as well as convergence within Government institutions. A key effort of FKAN has been to bring Safe water, Health and Nutrition perspectives together on this single issue, and on one platform.

Limbs of a Disaster – A typical twisting of limbs known as Genu Velgum in a very complex condition for a Skeletal Fluorosis affected woman. As fate, she accepts her condition and carries on with her daily life.

A Stigma from Water – A Walking stick is the only companion for many Skeletal Fluorosis affected patients in Nalgonda. Life moves around this stick, and it becomes more real than other humans around.

Young minds with new hope – Nutrition is the ray of hope for children, who are promised good food in Anganwadi and Mid-day meal programmes by new zeal of work. They will carry memories of this disease, and perhaps none else.

Threads of Recovery – Within gloom, few bright spots of recovery are seen more in Nalgonda now. Appropriate surgery at the right time saves this man from further deterioration and gives his family something to smile for.



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