

Nalgonda Collaborative

Tackling a Complex Regional Fluorosis Issue



FLUORIDE KNOWLEDGE AND ACTION NETWORK



March 2016

Nalgonda Collaborative: tackling complex regional Fluorosis issue



Background

Nalgonda Fluorosis: some facts

First Detected in India	1937 (Podili, Darsi, Kanigiri in Prakasam)
No of Mandals and villages highly affected	1108 Habitations in 59 Mandals
Fluoride greater than 2.5 ppm	484 habitations in 17 Mandals
Population estimated as affected	More than 3 lakh people with Skeletal and Dental fluorosis

The *Nalgonda Fluorosis* problem is a stigma that has stuck for generations. Severely disabling Skeletal Fluorosis affects lakhs of people in just one district of the country. The last official count of patients in 2001 was around 6.5 lakh affected Fluorosis patients and out of which around 75,000 severely Skeletal Fluorosis affected people.

All this has happened because of the extreme water stress and water scarcity situation in this region, resulting into 5.5 lakh deep borewells in just one single district! Quite naturally, the Fluoride problem has just increased over the past 80 years, after it first got reported in the 1930s.

A people's movement to demand Safe fluoride free water got momentum in the past few decades, and alongside political developments for a new Telangana state gave *Nalgonda Fluorosis* a new voice. All this culminated in two important developments, which were a) provision of surface water, mainly from Nagarjuna Sagar reservoir starting from 2005, and b) the push for a multi-department coordinated DFMC – District Fluoride Monitoring Centre – in 2012.

DFMC action: highlights	
First Constituted Date	Aug, 2013
Key Depts	RWS, Health, DRDA, Social Welfare, Women and Child Welfare, Civil Supplies
Key Programmes	Surface water supply to affected habitations and schools; Health ward; Tricycles to Disabled; Special Ration cards for additional rice; Replacement of Aluminum vessels; Milk and Eggs to children, Pregnant women and young Mothers ; Health detection programme by NPPCF; Rs 1500 per month pension to highly Skeletal Fluorosis affected people
Achievements till now	Converged programme of 17 line depts.; more than 900 habitations receiving Surface water;
Future Strategy	Village level capacity building in 1000 villages; Extension of Surface water to entire district; Professional management of DFMC

Given the magnitude of Surface water supply to the entire district, and the enormity of DFMC mandate, ranging from Safe water supply, Health detection, Nutrition based relief, Rehabilitation, and other activities, help was sought from the Fluoride Knowledge and Action Network (FKAN) in October 2013 towards further strengthening the DFMC institution and bringing in innovation happening in other places towards long term solution of the *Nalgonda Fluorosis* problem.

Activities

FKAN has played the role of understanding the status of efforts in Nalgonda, filling gaps in knowledge, and then developing future models of action in partnership with the environment of institutions in the region.

- i) Two Student studies were performed on the status of DFMC, and the on status of Surface water supply in Nalgonda. An ongoing study on Reverse Osmosis (RO) plants in Nalgonda attempts to look at the diverse models in action, how much access people have to these plants, and water management practices followed
- ii) An all NGO network meeting with conducted along with the DFMC to synthesize all efforts in the districts and to plan out further efforts
- iii) A specialized training on integrating Fluoride issues within Watershed programmes has been conducted and this is to be scaled up to the national Watershed programme
- iv) A specific focus has been on highly affected Marriguda Mandal where all departmental activities of `17 departments associated with the DFMC are being monitored in all 46 villages of the Mandal
- v) The Mobile based Caddisfly Fluoride water testing has been carried out in the entire Marriguda Mandal in partnership with Engineers Without Borders (EWB) students, to have a comprehensive Fluoride mapping and supplementing existing Fluoride data from government sources
- vi) Development of a people based reporting on Water supply is being developed

- vii) Helping the DFMC to conduct review meetings with the District Collector by following up and synthesizing Action Taken Reports (ATR) from concerned departments, preparing agenda and action plans for DFMC
- viii) Conducted two workshops with UNICEF, to bring together all stakeholders concerned with the Fluorosis issue in Nalgonda and bring them towards a comprehensive approach at tackling the problem



What do we learn

Engaging with *Nalgonda Fluorosis* gives us learning that are useful nationally to tackle the problem. Broadly we categorize these into issues concerning i) Safe Water, ii) Food and Nutrition, iii) Medical Relief and Rehabilitation and iv) Institutional Development and Sustainability

Safe Water

The current conditional of Surface water supply is highly appreciable, and much improved, but opens up the following avenues for development:

- i. Immediate safe water relief on a massive scale to Fluorosis affected people is being provided to good extent by Krishna and other surface water supply
- ii. Water supply gaps exist, both in terms of inaccessible areas, and non regular supply due to infrastructure maintenance issues, but increasingly, these are being sorted out.
- iii. People are going back to Fluoride affected water supply during the Water supply gaps, and otherwise 1/3 population in rural areas use RO drinking water supply
- iv. Towards the future, localized surface based water supply schemes need to be in place, based on local Water security and Watershed planning that ensures that no Water supply gap exists to affected people, so that they do not have to depend on payment based RO water that is water and energy wasteful

Nalgonda collaborative: highlights	https://storify.com/fluorideindia/nalgonda-collaborative
Constituted Date	Dec 3 and 4, 2014
Key Partner Institutions	UNICEF, DFMC, NIN, WASSAN
Main Activities	Knowledge and Institution building support to DFMC, Fluoride water supply monitoring programme, Rehabilitation development
Key Outputs	Developing UNICEF programme of engagement, Studies on DFMC and Water supply



Young minds with new
Hope

Food and Nutrition

Going forward from some food supply programmes, and ration card based provision, there is need to think hard at this important question in terms of:

- i. Though some provision of Special ration cards is in place for highly Skeletal Fluorosis affected people, focus is still on Rice and cereals. Shifting to non Fluoride affected food and increased nutrient (especially Calcium) intake is absent.
- ii. Special programmes for women and children continue in highly affected Mandals (17 out of 55), but this is not translating into an overall Food intake change and nutritional improvement.
- iii. Agriculture based Nutritional improvement programme is critical for Nalgonda as a combination of Millets growth and consumption; local Vegetable gardens; Poultry, and others to tackle the Food and nutrition crises on a large scale. Specific nutrient rich food (Calcium, Vitamin C and others) which can detoxify Fluoride from body need to be promoted and consumed.

Medical Relief and Rehabilitation

The current pension of Rs 1500 per month to severely Skeletal Fluorosis affected people covers around 40,000 persons. Though this is again a unique effort showing direction to rest of the country, there is much more to be done in terms of:

- i. Both severely skeletal Fluorosis affected and those with joint pains, are consuming highly potent Painkillers (Aceclofenac and others) constantly for years. This by itself is a serious problem affected kidney and liver
- ii. Patients need critical health care, as a combination of safe painkillers, Physiotherapy, Nutritional supplementation, Assistive devices, and in some cases, safe surgical procedures for corrective action.
- iii. A referral medical system as a combination of both private and public healthcare needs to be in place for both immediate relief through health centre based in Nalgonda, and special care through centres at Hyderabad and other places. These systems need to be free or highly subsidized so that affected people are able to take benefit

Institutional Development and Sustainability

Critical to coherent action on ground and benefits reach people with good impacts is development of institutions at all levels and capacity building to take current efforts into the future:

- i. At the root level, each Fluorosis affected habitation in Nalgonda needs to have a Fluorosis specific community resource person who can be the guide and repository of information for all action. This person would, along with the Gram Panchayat, coordinate all efforts with community for mitigating the problem
- ii. The DFMC is a unique institution of its kind. However, being the first one and also the harbinger of hope for other districts, there is need to nurture this and others DFMCs with a support advisory group which can guide its working and make it more effective. It needs to have participation from community resource persons, and act as a watchdog for Fluorosis action.
- iii. Regionally, NIN, UNICEF and other institutions are playing a key role. Their work spans beyond Nalgonda and is useful for other areas as well. The proposed Fluorosis research and Rehab centre of NIN needs to be taken ahead, and UNICEF Hyderabad would need to take the lead in spearheading the Nalgonda experience to all of Fluorosis affected districts of Telangana and Andhra Pradesh

Policy learning from Nalgonda

Institutional Convergence

Professional support needed to manage large multi department convergence. Special issue based support is needed for local institution

Large Scale water supply system

Transparent monitoring system is helpful in improving quality of overall Water supply system. Alternatives need to be in place for contingencies

Nutrition and Medical Relief Rehabilitation

Referral system and patient support is needed for highly affected people. Apart from pensions, people need relief from pain and other suffering.

Future work of FKAN

As described in this note FKAN is engaged in varied activities for mitigating *Nalgonda Fluorosis* in partnership with the range of stakeholders that are contributing together. Going into the future, the following activities could be summarized:

i) DFMC support in Nalgonda and Prakasam

In collaboration with UNICEF, there is now thinking to support and develop DFMC Nalgonda, and also meanwhile look at the possibility of this institution in other districts, first starting from Prakasam in AP. A workshop was conducted in Nalgonda for this purpose, and now steps are being taken to take this idea forward to Prakasam as well.

Status: UNICEF is working on a proposal for this initiative.

ii) Health Relief and Rehab system

Voluntarily, several private hospitals from Hyderabad have been providing relief based work to Nalgonda Fluorosis patients. However, these have been few in number and not coordinated. We aim to expand the scope of public and private partnership in Health and relief based Rehabilitation for Fluorosis patients. We expect that there exists ample goodwill in Hyderabad based specialist hospitals who would come forward to help Fluorosis affected people. This would be coordinated through a Nalgonda based community based detection, symptomatic relief and referral unit.

Status: We are looking for benefactors for this initiative.

iii) Water supply monitoring and Water grid

The Nalgonda surface Water supply programme is soon planned to be expanded all across Telangana. This is known as the Telangana Water Grid. With independent observation and monitoring, there is ample scope to improve current efforts and reduce the water supply gaps to community along with reporting of quality of water being supplied. Our effort with Caddisfly, monitoring of water supply, and development of people's based reporting is a step in this direction.

Status: Piloting of efforts completed. Future is to develop a civil society based partnership to scale up across Nalgonda to report and monitor surface Water supply

iv) Food and Nutrition support development

There is incomplete information on what changes need to be made by Government programmes and by community themselves to bring about a lasting change in both prevention from Fluoride free food and in enhancing Nutrition to develop resistance to mitigate Fluorosis. Firstly, this is being dealt with by developing field based information on what changes need to come on. Secondly, we plan to pilot agriculture based interventions through the Watershed programme, with a dual aim of diluting affected groundwater used for irrigation, but also developing specific Nutrition gardens for tackling Fluorosis.

Status: Food and Nutrition plan in development; Watershed programme partnership being developed

Future work with Nalgonda collaborative

DFMC Partnership	Support to Institution and effective functioning. Communication development support and capacity of village level institutions
Exporting learning to other places	Transporting DFMC thinking to other places such as Prakasam and other parts of the country
Developing School based Water testing and Mitigation Programme	Involving Students in Testing of Water and Developing them as change leaders on the issue
Developing Rehabilitation and Nutrition support programme in Nalgonda	Referral system with local resource centre along with key hospitals in Hyderabad is being proposed to help highly affected people from their suffering



References

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3. K Sen, Status of Water supply in Nalgonda, Student report
4. Workshop report, 2014, 2015
5. 2001, Govt Medical report on Fluorosis patients in Nalgonda

Key Persons

Mr Srinivas Chekuri Dr Arjun Khandare, NIN Mr Subhash Kanchikotla Mr Sadguru Prasad

Mr Ramachandrudu, WASSAN Ms Suneetha Sapur, Akshaya Dr Raja Reddy



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.

@fluorideindia on twitter

Facebook group fluorideindia

@fluorideindia on Medium

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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.