



# Indian Medical Parliamentarians' Forum Newsletter

Vol. 11, No. 3

Winter Session Issue

December 2025

Health must stay at the heart of lawmaking. This Winter Session 2025 issue of the IMPF Newsletter turns to urgent priorities before Parliament.

As committees meet and budgets tighten, evidence must guide choices that affect patients and families daily. We open with Type 1 diabetes and call for assured insulin, monitoring supplies, and school readiness. Our chronic kidney disease article shows how simple tests and early counselling can avert costly dialysis. We then spotlight Neurofibromatosis Type 1 and urge recognition under the National Policy for Rare Diseases. Prevention runs through this edition.

We examine antimicrobial resistance, India's antibiotic emergency, and the need for stewardship across people, animals, and the environment. Kerala's emerging rare disease model offers a workable template that blends early detection, pooled procurement, and state support. We also survey a rare disease financing gap, where children on enzyme therapy risk stoppage after the one-time cap. Together, these articles offer a clear message: protect continuity of care, invest early, and measure delivery

We thank every author and expert for their time and rigour. Their insights strengthen IMPF's mission to place health at the centre of India's development agenda.

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## Type 1 Diabetes: An Opportunity to Heal, An Opportunity to Help

Type 1 diabetes tests India's promise of health. It strikes children and young adults, demands lifelong insulin, and punishes delays every day. Unlike type 2 diabetes, it is autoimmune, sudden, and unforgiving of gaps. Yet policy often treats it as a footnote – too few to notice, too common to qualify as “rare”.

About a million Indians live with this condition and need reliable insulin, monitoring supplies, trained providers, and safety in schools. These needs are practical, affordable, and measurable within public programmes. Meeting them can prevent emergencies, protect futures, and show what rights-based care looks like – especially for families beyond specialist endocrine centres.

Diabetes care represents a unique challenge. India is home to the world's second-largest diabetes burden. Over 89 million Indian adults live with diabetes, and another 127 million with prediabetes. Most have type 2 diabetes, which is common among adults. A smaller group has type 1 diabetes. Though it shares the name, type 1 diabetes differs in cause, course, complications, and care. People living with type 1 diabetes experience near-total failure of pancreatic beta cells. This usually follows an immune reaction and may occur after a severe viral fever. They need lifelong insulin, regular check-ups, and sustained support.

Because their number is relatively small, the voice of people living with type 1 diabetes is often unheard. Their medical and psychosocial needs are addressed in specialist endocrine centres, but not across most public health systems. India does have a programme for rare and orphan diseases. Type 1 diabetes, however, does not fall in the “rare” category. Paradoxically, it gets less attention. This is unfortunate because the requirements for type 1 diabetes are relatively easy to meet. Their numbers, too, will not overwhelm the public health system.

This is where policy must step in with intent and money. First, India needs a clear national pathway for type 1 diabetes within NCD programmes, with assured budgets for insulin, glucometers, strips, and ketone testing. Second, procurement and distribution must treat these as essential supplies,



not optional add-ons, and prevent stock-outs at public facilities. Third, school health guidelines should mandate safe storage, trained staff, and emergency protocols for hypoglycaemia. Finally, regulatory support for quality-assured devices, standardised data registries, and periodic audits will make care accountable and equitable.

With modern treatment, people with well-controlled type 1 diabetes can enjoy optimal health. The Indian pharmaceutical industry produces high-quality insulin, used at home and exported worldwide, including to the USA. The Endocrine Society of India, along with sister organisations, leads awareness campaigns on type 1 diabetes.

A concerted policy push on type 1 diabetes can yield major dividends. Beyond improving the lives of children, adolescents, and young adults, India can emerge as a global soft power in type 1 diabetes care. With economical, effective insulins and capable, empathic endocrine teams, we can make a meaningful difference worldwide. Our medical and pharmaceutical support can build bridges of fellowship with other countries. Through type 1 diabetes advocacy, we can also uphold lokasamgraha – the welfare of the world – as the Bhagavad Gita enjoins (3:20).

A century ago, type 1 diabetes was seen as a curse, even a death sentence. Today, it offers India an opportunity to help, to heal, and to live our values of humane humanity. As we often reaffirm: *vasudhaiva kutumbakam*.

--Dr Sanjay Kalra, Karnal, Haryana &  
Dr Shivani Sidana, AIIMS Bathinda, Punjab

## Recognising Neurofibromatosis Type 1 (NF1) under NPRD: A National Policy Imperative for India

Neurofibromatosis type 1 (NF1) is a rare, complex genetic condition with a prevalence of about 1 in 3,000 to 1 in 5,000. It is caused by mutations in the NF1 gene, resulting in overactivation of growth pathways that drive abnormal cell proliferation and survival. As a heritable condition, it can affect multiple family members. NF1 is highly heterogeneous, with variable expression among patients and even among family members with identical mutations. Its multisystem manifestations include tumour growth, skin manifestations, bone dysplasia, ocular problems, and neurological complications such as cognitive impairments and learning disabilities. Most patients are diagnosed in childhood. Although many have a normal lifespan, average life expectancy is reduced by 8–15 years, largely due to an increased risk of malignancy.

Plexiform neurofibroma (PN) is a non-malignant, often progressive and invasive nerve sheath tumour occurring in 30–50% of patients with NF1. It can arise anywhere in the body and cause major morbidities, including pain, disfigurement, and motor deficits; severe cases may lead to life-threatening complications such as airway obstruction. These morbidities substantially impair quality of life, affecting emotional well-being, sleep, physical activity, and social functioning.

Data from the National Cancer Institute's Natural History shows PN growth is often rapid in younger children, with deep emotional impacts on children and families. PN rarely shrinks spontaneously without effective treatment, and the burden accumulates through childhood and persists lifelong.

The psychosocial toll is profound. Visible tumours and deformities often lead to stigma, bullying, social isolation, and discrimination in schools, workplaces, and public spaces. Repeated interventions, financial strain, and marginalisation burden patients, families, and carers.

Despite this, NF1 remains under-recognised within India's healthcare and policy ecosystem. Awareness among healthcare providers is limited. Referral pathways are fragmented, and access to multidisciplinary care is inconsistent. Critically, NF1 is not explicitly recognised under India's National Policy for Rare Diseases (NPRD). This limits access to specialised care, innovative therapies, financial assistance, and rehabilitation,

pushing families into a costly, confusing system.

Patient advocacy groups across India have become a lifeline, building networks and amplifying patient voices despite scarce resources. Scientific advances have reshaped NF1 care. Targeted therapies can reduce tumour burden, alleviate pain, and preserve

function, particularly for inoperable plexiform neurofibromas. Yet access to these treatments in India is constrained by cost, availability, and lack of reimbursement; without NPRD recognition, they remain out of reach for most.



Disability assessment is another gap. Many NF1-related impairments—chronic pain, fatigue, cognitive difficulties, and psychological distress—are invisible and fluctuating. Existing disability frameworks, including the Rights of Persons with Disabilities Act, 2016, inadequately capture functional impairment in NF1.

A coordinated national response is urgently needed. Formal recognition under the NPRD would enable systematic NF1 care within Centres of Excellence, with streamlined referrals, multi-disciplinary teams, India-specific Standard Treatment Guidelines, provider training, patient registries, and structured engagement with advocacy organisations.

Recognising NF1 under the NPRD is not merely policy—it is a moral and public health imperative. With timely diagnosis, appropriate treatment, rehabilitation, and social support, people with NF1 can lead dignified, productive lives. India must act decisively so that no person living with NF1 is left unseen, unheard, or unsupported.

**- Dr Byreddy Shabari, Member of Parliament**

**- Prof. (Dr.) Sankar V. Hariharan, HoD,  
Department of Genetics, Child Development  
Center, Thiruvananthapuram, Kerala**

## Rare Disease Management in India: Past, Present, and the Road Ahead

For decades, rare diseases remained a neglected health challenge in India. Individually uncommon yet collectively significant, they affect an estimated 70–96 million Indians. The story of rare disease management is one of late recognition, gradual policy awakening, and cautious optimism for the future.



hormone and treatment for SMA—at centres such as SAT Hospital, a Centre of Excellence under NPRD 2021. The model blends early detection, multidisciplinary care, pooled procurement, and state funding, strengthened by partnerships and crowdfunding, to ease barriers. Kerala's hub-and-spoke

approach and registry efforts offer a replicable framework.

**The Past: Neglect, Delay, and Despair**  
Historically, rare diseases in India were marginalised within the health system. Limited awareness among healthcare providers, weak diagnostic capacity, and minimal research led patients to endure years-long diagnostic odysseys. Genetic testing was scarce and expensive, newborn screening was limited, and treatment options—often imported orphan drugs—were prohibitively costly. Families faced catastrophic out-of-pocket expenses, usually leading to discontinuation. Public health programmes focused on communicable and non-communicable diseases, leaving rare diseases outside policy priorities.

**The Present: Policy Recognition and System Building**  
The last decade has marked a turning point. The launch of the National Policy for Rare Diseases (NPRD) in 2021 by the Ministry of Health and Family Welfare signalled recognition of rare diseases as a public health concern. The policy introduced disease categorisation, identified Centres of Excellence, and proposed financial assistance for selected conditions.

Parallely, advances in genomics, expanded medical genetics services, and the growing role of patient advocacy groups have strengthened the ecosystem. Public insurance platforms such as Ayushman Bharat have begun limited engagement with high-cost therapies, while indigenous pharmaceutical and biotech sectors are exploring orphan drug development. Digital registries and improved surveillance are slowly generating India-specific epidemiological data.

Kerala has emerged as a model through state initiatives, including KARE (Kerala United Against Rare Diseases), which aims to provide accessible care statewide. Launched in 2024, KARE offers free access to costly therapies—including growth

Yet challenges remain. Funding gaps, uneven geographic access to Centres of Excellence, limited coverage of high-cost therapies such as enzyme replacement and gene therapy, and ethical dilemmas around prioritisation continue to strain the system.

**The Future: From Compassionate Care to Precision Public Health**  
The future of rare disease management in India lies in integration, innovation, and indigenisation. Universal newborn screening for selected treatable conditions can shift care from late-stage palliation to early intervention. Expanding genomic diagnostics at district and state levels will shorten diagnostic delays. Indigenous manufacturing of orphan drugs, public-private partnerships, and outcome-based pricing models can improve affordability.

Equally important is embedding rare diseases within existing maternal, child health, and non-communicable disease frameworks—transforming them from “rare” concerns into integral components of health planning. Patient registries, real-world evidence, and ethical priority-setting will guide sustainable financing. With emerging gene and cell therapies on the horizon, India can move from being a late adopter to a global leader in cost-effective rare disease care.

India's journey in rare disease management reflects a broader evolution of its health system—from survival-focused care to equity-driven, technology-enabled healthcare. Although the road ahead is complex, sustained policy commitment, scientific innovation, and patient-centred governance can ensure that rarity no longer determines destiny.

– Dr. Rahul U R  
State Nodal Officer Child Health & Rare  
Diseases, NHM, Kerala

## Kidney Disease: The NCD We Can Prevent with Early Care and Awareness

Kidney disease, especially chronic kidney disease (CKD), is a long-term illness that affects millions of people, yet it often goes unnoticed until it becomes severe. While diseases such as diabetes and heart disease are commonly discussed, kidney disease receives less attention, even though it is closely linked to both. CKD develops slowly and silently, and many people are unaware their kidneys are being damaged until they reach an advanced stage, when treatment becomes difficult, expensive, and life-changing. For patients and families, late diagnosis of kidney disease can be devastating. When kidney problems are detected only at a late stage, patients may require dialysis or a kidney transplant to survive. In many cases, families struggle to afford long-term treatment, leading to

Early detection offers clear and meaningful benefits to patients. When kidney disease is identified early, doctors can advise patients on healthy eating, reducing salt intake, staying physically active, controlling blood glucose and blood pressure, and taking appropriate medicines. These steps can slow kidney damage, delay or prevent the need for dialysis, and allow patients to live healthier, more productive lives. The unsafe and prolonged use of painkillers and certain unregulated medicines is a common but under-recognised cause of kidney damage. Public education about safe medicine use and clear guidance from healthcare providers can prevent many cases of kidney injury. Patients should be encouraged to consult doctors before taking medicines regularly, especially if they

**Table 1: How Preventive Policies Can Protect Kidney Health and Help Patients**

| Preventive Policy                                                   | What This Means                                               | How Patients Benefit                                |
|---------------------------------------------------------------------|---------------------------------------------------------------|-----------------------------------------------------|
| Routine kidney tests for people with diabetes & high blood pressure | Kidneys are checked before problems become serious            | Kidney disease is found early & treated on time     |
| Education on a healthy lifestyle & diet                             | People learn how food, exercise, & habits affect the kidneys  | Lower risk of kidney damage & better overall health |
| Training of doctors & health workers                                | Kidney problems are recognised early at nearby health centres | Faster care without long travel or delays           |
| Public awareness about unsafe medicines                             | People avoid medicines that can damage the kidneys            | Fewer cases of preventable kidney injury            |
| Support for affordable dialysis & transplant care                   | Treatment costs are reduced & made accessible                 | Patients survive longer without financial hardship  |
| Community awareness campaigns                                       | Simple messages reach people before illness develops          | People seek help early & protect their kidneys      |

serious social and economic consequences. This is why kidney disease must be addressed not only as a medical issue but also as a major public health and policy concern.

Kidney disease is strongly linked to common conditions such as diabetes and high blood pressure. People with these conditions face a much higher risk of developing CKD over time. At the same time, kidney disease itself increases the risk of heart attacks and strokes. For patients, this means kidney disease often worsens overall health and leads to repeated hospital admissions. From a health system perspective, ignoring kidney disease reduces the effectiveness of programmes aimed at controlling diabetes and heart disease. The most encouraging aspect of kidney disease is that it is largely preventable and can be managed effectively if detected early. In the early stages, CKD can be identified through simple, low-cost tests such as blood pressure measurement, blood glucose testing, urine protein testing, and a kidney function test.

already have diabetes or high blood pressure. Table 1 shows how preventive policies can protect kidney health and support patients living with CKD. Strong primary healthcare systems are essential for preventing kidney disease. Health policies that support affordable dialysis and fair access to kidney transplantation are equally important for patients. The national organ and tissue transplant organisation (NOTTO) of our country is doing great work in this area.

**– Dr Sourabh Sharma**

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VMMC and Safdarjung Hospital, New Delhi  
Chair, Dialysis Working Group, International Society  
of Nephrology  
Executive Council, Indian Society of Organ  
Transplantation

**– Dr Himanshu Verma**

Professor, Department of Nephrology, VMMC and  
Safdarjung Hospital, New Delhi

## AMR: India's Antibiotic Emergency

Antimicrobial resistance (AMR) is one of the most serious public health challenges of the 21st century. It occurs when the antibiotics we use to treat infections stop working effectively because bacteria and other microbes become resistant to them. This makes common infections harder and more expensive to treat, increasing the risk of death and exerting pressure on already overburdened health systems. Low- and middle-income countries are particularly affected, and India faces a particularly high burden due to its large population and high antimicrobial consumption.

Annually, AMR causes an estimated 1.14 million deaths and is associated with 4.71 million deaths worldwide, with the highest burden in sub-Saharan Africa and the South Asia region, including India. Without effective action, AMR-related deaths could reach 8.22 million by 2050. In India, it's estimated that 267,000 deaths were directly attributable to AMR and 987,000 were associated with AMR in 2021, with mortality now concentrated among older adults. India ranked 57<sup>th</sup> globally in age-standardised AMR mortality.

India is currently the world's largest consumer of antibiotics. While these medicines save lives when used appropriately, excessive and inappropriate use has led to a growing number of infections that are difficult to treat. Resistant infections often require longer hospital stays, more expensive medicines, and specialised care, increasing costs for both families and the health system. This trend threatens the quality and safety of healthcare delivery, particularly in hospitals.

The drivers of AMR extend well beyond hospitals and clinics. Antibiotics are widely used in animal husbandry, fisheries, and agriculture, sometimes for growth promotion rather than treatment. In human health, over-the-counter availability of antibiotics, self-medication, incomplete treatment courses, and limited public awareness contribute significantly to misuse. In addition, pollution from pharmaceutical manufacturing, livestock waste, and poorly managed hospital waste allows resistant organisms to spread in the environment. These interconnected factors mean that AMR cannot be addressed solely by the health sector.

Reducing inappropriate antibiotic use requires a practical, system-level action. Stronger



enforcement of prescribing guidelines for antibiotic sales, better access to affordable diagnostic tests to guide treatment decisions, and wider implementation of antimicrobial stewardship programs in both public and private healthcare facilities are critical. Supporting healthcare providers and pharmacists to follow rational prescribing practices, while educating the public that antibiotics are not needed for all illnesses, is essential. Antibiotics must be treated as a shared national resource, not as routine consumer products.

India has taken important steps to address AMR through the launch of the National Action Plan on Antimicrobial Resistance 2.0 (NAP-AMR 2.0), which places AMR firmly on the national health policy agenda. The first action plan helped build awareness but faced challenges, including weak coordination across sectors, uneven adoption by states, limited surveillance capacity, and disruptions caused by the COVID-19 pandemic. Ongoing issues, such as over-the-counter antibiotic sales, gaps in the regulation of animal and agricultural uses, limited funding, and insufficient research and innovation capacity, continue to slow progress.

Addressing antimicrobial resistance in India now requires clear and sustained policy action. Effective implementation of the National Action Plan on Antimicrobial Resistance 2.0 will depend on adequate and sustained financing, strong coordination across ministries and states, and clear accountability mechanisms. With timely and coordinated action, India can slow the spread of resistance, protect the effectiveness of life-saving medicines, and safeguard health and development gains for future generations.

– Dr S. S. Lal  
Director, ReAct Asia Pacific  
Member, ReAct's Global Leadership Team

## From Allocation to Access: Why India Needs a Focused Strategy for Life-Saving Rare Disease Care

India's rare disease policy architecture is at a critical juncture. The National Policy for Rare Diseases (NPRD) 2021 marked an important shift by acknowledging the clinical and financial realities faced by patients with rare and ultra-rare conditions. However, emerging implementation trends indicate a growing disconnect between policy intent, budgetary provision, and patient outcomes—most acutely for those dependent on uninterrupted, life-saving therapy.

Available government data indicate a significant implementation gap. Of the total budgetary outlay for rare disease treatment under NPRD 2021 for FY 2025–26, only about 10.28% has been utilised so far. While allocations reflect intent, low utilisation constrains the system's ability to expand treatment coverage to eligible patients and sustain care for those already receiving therapy. For progressive and fatal conditions, delayed utilisation has direct clinical consequences.

Rare diseases affect small populations, yet their impact is severe and enduring. This is particularly true for ultra-rare Lysosomal Storage Disorders (LSDs)—inherited, progressive conditions that often present in early childhood and, if untreated, lead to irreversible organ damage and premature mortality. Management of LSDs requires lifelong enzyme replacement therapy. These are not episodic interventions; interruption leads to rapid progression, loss of functional gains, and often irreversible decline. Continuity of care is therefore a clinical necessity.

It is precisely this continuity that is under strain. An estimated 100 patients across India—most of them young children—have exhausted the one-time financial assistance cap of ₹50 lakh per patient under NPRD 2021. These patients were among the earliest beneficiaries and had successfully initiated treatment. Today, despite remaining clinically eligible and having approved therapies available, they face discontinuation solely because the cap has been exhausted. In such cases, discontinuation is not merely disruptive; it is life-threatening.

This reveals a narrow but severe policy blind spot. Patients exist, treatments exist, funds exist; what is missing is a focused mechanism to bridge patients beyond the initial cap and ensure sustained care for those already on therapy. The paradox is evident: while allocated funds risk remaining unutilised by year-end, children stabilised on



treatment face deterioration due to financial exhaustion.

From a fiscal and administrative standpoint, the solution is both limited and feasible. An interim allocation of approximately 50 crore—equivalent to 50 lakh per patient for this finite cohort—would be sufficient to ensure one additional year of uninterrupted treatment for these ~100 patients. This can be accommodated within the existing FY 2025–26 allocation without seeking additional approvals. What is needed is targeted prioritisation and time-bound disbursement.

Delays have serious consequences. Humanitarian risks are immediate and irreversible, with avoidable morbidity and mortality among children already receiving treatment. There are also governance implications: allowing approved funds to remain unspent while approved patients go untreated undermines confidence in outcome-based budgeting and policy execution, and risks reducing NPRD 2021 to a framework of intent rather than impact.

India has taken important steps in the rare disease space, including expanding designated Centres of Excellence and making budgetary provisions for diagnosis and treatment. What remains lacking is a humane and responsive approach for patients who fall through narrow implementation gaps—particularly those who have exhausted support despite clear clinical need.

Bridging this gap does not require new architecture. It requires ensuring that existing frameworks respond with urgency, compassion, and continuity of care. In rare diseases, the cost of delay is measured in lives.

– Srashti Dubey  
Coordinator-Patient Advocacy Group &  
– Siddhartha Kashyap, Public Health Expert

## MoHFW issues updated Health Advisory on Air Pollution (Oct 2025)

The Ministry of Health and Family Welfare, through NCDC's National Programme on Climate Change and Human Health (NPCCHH), has released an updated Health Advisory on Air Pollution to help State health departments reduce illness linked to air pollution. The advisory outlines key pollutants—especially PM2.5/PM10, ozone, nitrogen dioxide, sulphur dioxide, and carbon monoxide—and identifies major sources, including vehicles, industrial emissions, road dust, construction, waste burning, solid-fuel cooking, and indoor triggers such as mosquito coils and incense.

It also clarifies how the Central Pollution Control Board's Air Quality Index (AQI) categories—from "Good" to "Severe"—should inform public health messaging and behaviour. As the AQI worsens, complications rise sharply among vulnerable groups, including children, older people, pregnant women, people with cardio-pulmonary disease, and outdoor workers. The advisory lists common warning symptoms such as eye and throat irritation, cough, wheeze, breathlessness, chest discomfort, headache, and giddiness, and links long-term exposure to chronic respiratory and cardiovascular disease, lung cancer, and premature deaths.

For preparedness, the advisory recommends that States routinely track the daily AQI (including via CPCB tools), share data with health facilities, intensify IEC during high-risk periods (winter, stubble-burning days, post-Diwali), and strengthen emergency and OPD readiness. It also highlights air-quality forecasting through the Air Quality Early Warning System and suggests sentinel surveillance and dedicated CHEST clinics for risk screening and standard care during peak months.



## Tobacco Free Youth Campaign 3.0 Launched to Shield Youth from Tobacco

Union Minister of State for Health and Family Welfare, Smt. Anupriya Patel launched the Tobacco Free Youth Campaign (TFYC) 3.0 at a hybrid event in Delhi on October 9, 2025. She warned that children are especially vulnerable to early experimentation with cigarettes, bidis and smokeless products, which can lead to lifelong addiction and premature deaths.



Patel said India has tightened tobacco control by mandating health warnings and anti-tobacco messages for tobacco depictions on films, TV and online platforms, banning tobacco advertising and sponsorship, and requiring large pictorial warnings on packs. She reiterated that sales to minors and sales within 100 yards of educational institutions are prohibited, and that electronic cigarettes are banned.

The 60-day TFYC 3.0 will intensify public awareness, strengthen compliance with Tobacco-Free Educational Institutions guidelines, enforce COTPA 2003 and PECA 2019, expand tobacco-free villages, boost digital outreach, and build capacity for cessation. The campaign also aligns with the Nasha Mukht Bharat Abhiyan and calls for a "whole

of government" approach.

At the launch, participants took a 'Say No to Tobacco' pledge, new school resources were released, and a fourth National Tobacco Testing Laboratory was dedicated at NIMHANS, Bengaluru. Officials said earlier editions declared thousands of institutions and villages tobacco-free.

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Printed at Apex Printing House, New Delhi-110067, Ph: 9818114996.