In this issue

Rare Diseases in India

Focus on policy issues

India defines rare diseases as those that affect less than 500,000 people in the country. Since there are more than 450 reported rare diseases, there are millions of people with rare diseases in India.

Since these diseases are rare, doctors are not conversant with the signs and symptoms. Even if doctors suspect the possibility of such cases in patients, diagnostic tests are not easy. Most rare diseases are genetic and the facilities for testing are also rare in India. Even if the tests are done and the diseases are confirmed, drugs for treatment are also rare. Even if the drugs are available, they are costly because most drugs for rare diseases have to be imported. Since there are very few patients in each category of rare disease, pharmaceutical companies do not find it viable to do research and development or market the 'orphan' drugs. In effect, most patients of rare diseases die young, without ever being diagnosed. Hence even data on rare diseases in India suffer from gross underreporting.

In a General Article in this issue, Anjali Taneja, L. S. Shashidhara and Alok Bhattacharya from the Ashoka University examine the actions taken on the issue by other countries and inquire why India is lagging behind.

Though a National Policy for Rare Disease was released in 2017, there were glaring lacunae in the document since not all stakeholders were consulted for formulating the policy. A revised draft of the policy introduced this year is still under consultation. Though a National Initiative on Rare Diseases was launched in 2017 by the ICMR, even data collection on rare diseases is yet to be initiated properly. Though there is a financial assistance scheme for poor patients with rare diseases under the Rashtriya Arogya Nidhi fund allocation, the process of disbursement is yet to be streamlined.

So what can and needs to be done? Turn to **page 1500** for a comprehensive list of recommendations.

High Value Crops

Diversification in eastern India

Farmers in eastern India have traditionally focussed on growing grains. A history of drought and famine narrowed the focus of the farmers to filling hungry stomachs. But the times have changed. India's granaries are overflowing. The focus, therefore, needs to shift to the nutritional and income security of farmer families and the sustainability of agricultural practices. Diversification from rice monocropping to high value crops such as fruits, vegetables and flowers can increase gross returns from one hectare of land to more than a lakh rupees per year.

Why then are farmers not adopting the strategy? What factors influence farmers in eastern India to diversify into growing high-value crops? How much land should farmers allocate to high-value crops to optimise returns from unit land area?

Researchers from the ICAR and the International Food Policy Research Institute collaborated to find out. Read their Research Article on the issue. Turn to **page 1575** in this issue.

High Entropy Alloys

The alloy of copper and tin came to be considered the representative of the beginning of a new era in human prehistory. From the Bronze Age, we have come far: from stainless steel in kitchens to the duralumin used in making aircraft, alloys pervade our day to day lives. Most of these alloys have only two or three elements. In the beginning of the 21st century, the subject of alloys has become a hot topic again, with theoretical developments on high entropy alloys: alloys with five or more elements in equal or near-equal proportions.

Nilesh P. Gurao and Krishanu Biswas from IIT Kanpur provide us insights about high entropy alloys in a Review Article on **page 1520** in this issue. Given the available experimental tools, large amounts of digital data and computational tools, the fields of high entropy materials, in general, and high entropy alloys, in particular, are poised to provide us properties that are useful for a wide range of applications.

Lead-free Piezoceramics

Single crystalline quartz minerals generate electricity when pressure is applied or generate pressure when electricity is applied. This discovery by the Curie brothers created excitement. Such piezoelectric materials could potentially be used as pressure sensors, transducers, actuators and even as harvesters of mechanical energy. Imagine the pressure of foot falls in a room creating the energy needed to light it up!

But, unfortunately, the electricity generated by quartz crystals is too small.

The discovery of ferro-electricity in oxide ceramics soon after the Second World War fired up the imagination. Such ceramics are not only easy to prepare, they also show nearly 200 times better piezoelectric response than quartz.

But, unfortunately, the best piezoceramics, commonly known as PZTs, contained lead – toxic and, therefore, not too safe to use.

The Review Article by Rajeev Ranjan on lead-free piezoceramics based on sodium bismuth titanate will fire your imagination again. But high-performance actuators are now on the horizon of reality. Read on from **page 1507**.

Fruiting Habit Traits of Chilli

Chillies originated in Mexico and diversified in South America. But it is India that leads in production. So researchers from the University of Agricultural Sciences had reasons to examine the fruiting habits of the chilli plant.

The fruits of the hot pepper plant may be solitary or clustered. The fruits could be pendant or erect. In a Research Communication on **page 1598** in this issue, read about the genetics behind the traits.

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