

News from here and there

'Research' theme for Rare Disease Day 2017

'Research' is the theme for the Rare Disease Day 2017. In 2008, EURORDIS (Rare Diseases Europe) and its Council of National Alliances formally announced that the last day of February each year would be recognized as Rare Disease Day. The aim of designating such a day was to raise awareness among the general public, policy-makers, researchers, health professionals, pharmaceutical industry and the media about rare diseases and to initiate research for finding the cures for such diseases. This association now represents 755 rare disease patient organizations in 67 countries amounting to 30 million people affected by rare diseases throughout Europe.

The year 2017 marks the 20th anniversary of EURORDIS, a non-governmental alliance formed and run by patients and patient organizations dealing specifically with rare diseases. The ongoing campaigns to create awareness about rare diseases has led to European Union legislations offering pharmaceutical companies incentives to develop orphan medicines and to the creation of national rare disease strategies and specialized centres of care in most of the European Union member states.

Research is needed to decipher the origin, progression and treatment options for rare diseases which tend to affect a very small fraction of society, but have a genetic base in almost 80% of patients. Infections, allergies and environmental factors have been identified as causative agents in the remaining 20% of patients. The diseases, which may be degenerative or proliferative, have 50% of patients in paediatric age groups. Some of the rarest diseases in the world include Hutchinson–Gilford Progeria, Fields' Disease, Fibrodysplasia Ossificans Progressiva, Von Hippel–Lindau disease, microcephaly, Paraneoplastic Pemphigus and Morgellons.

Mr Prasanna Kumar B. Shirol, co-founder ORDI (Organization for Rare Diseases India) and founder and former president of LSDSS (Lysosomal Storage Disorder Support Society) told this correspondent, in an e-mail, 'It is ironic that while the number of patients with rare diseases is increasing every year, there is no treatment for more than 95% of the diseases and patients can, at best, depend only on supportive therapy. Awareness, accessibility and affordability are key needs of patients suffering from rare disease. Developing innovative therapy options for more and more rare diseases would provide relief to a lot of patients and families. It is important that research is done in the area of other such diseases so that patients suffering from them have an option of leading healthier and active lives. For this, support would be required from the government to build a conducive infrastructure where drugs and therapies are more accessible for different rare disease patients.'

MAHARRA HUSSAIN, *Dubai, United Arab Emirates*

WHO list of antibiotic-resistant priority pathogens with the greatest threat to human health

On 28 February 2017, WHO published its first global priority list of antibiotic-resistant pathogens that pose the greatest threat to

human health. This list is a tool to guide and promote research and development of new antibiotics, as part of WHO's determination to check the alarming global resistance to antimicrobial agents.

The list aims to encourage governments to have policies that will boost basic science, and research and development by both government agencies and the private sector. It will offer guidance to new research and development strategies such as the WHO Drugs for Neglected Diseases initiative (DNDi).

The list was developed in partnership with the Division of Infectious Diseases, University of Tubingen, Germany. The criteria for selecting the pathogens were: the severity of the infections caused; length of hospital stay; resistance to existing antibiotics; spread in the community; spread between animals, between animals and humans and person to person transfer; available treatment options; prevention measures and whether new antibiotic options are available in the research and development pipeline.

The list has been divided into three categories according to the urgency for new antibiotics—critical, high and medium priority:

Priority 1 (Critical)

- Carbapenem-resistant *Acinetobacter baumannii*
- Carbapenem-resistant *Pseudomonas aeruginosa*
- Carbapenem-resistant, ESBL (extended-spectrum β -lactamase)-producing *Enterobacteriaceae*

Priority 2 (High)

- Vancomycin-resistant *Enterococcus faecium*
- Methicillin-resistant, vancomycin intermediate and resistant *Staphylococcus aureus*
- Clarithromycin-resistant *Helicobacter pylori*
- Fluoroquinolone-resistant *Campylobacter* species
- Fluoroquinolone-resistant *Salmonella* species
- Cephalosporin-resistant, fluoroquinolone-resistant *Neisseria gonorrhoeae*

Priority 3 (Medium)

- Penicillin non-susceptible *Streptococcus pneumoniae*
- Ampicillin-resistant *Haemophilus influenzae*
- Fluoroquinolone-resistant *Shigella* species

The most critical group in the list highlights the threat posed by multi-drug resistant gram-negative bacteria such as *Acinetobacter baumannii*, *Pseudomonas aeruginosa* and various *Enterobacteriaceae* (including *Klebsiella*, *Escherichia coli*, *Serratia* and *Proteus*). These bacteria are able to find new ways to resist treatment and then pass along the genetic material to other bacteria making them drug resistant as well. They pose serious threats in hospitals, nursing homes, and among patients on devices such as ventilators and blood catheters. These bacteria can cause serious, often lethal, infections such as bloodstream infections and pneumonia.

The priority 1 group of organisms have become resistant to multiple groups of antibiotics, including the carbapenems and third generation cephalosporins, the only available antibiotics for these organisms.

The high and medium priority group bacteria include those that

are becoming increasingly drug-resistant and that cause more common diseases such as gonorrhoea and food poisoning.

Mycobacterium tuberculosis, which is becoming highly resistant to traditional treatment, was not included in the list as it is targeted by other dedicated programmes.

To address antibiotic resistance, research and development is essential, but it is not a stand-alone solution. Coupled with this must be better prevention of infections, correct use of antibiotics in both livestock and humans, and the rational use of any new antibiotics that may be developed in the future.

P.M. NISCHAL, *Bengaluru, Karnataka*

Benchmarks for publications defined by the MCI and the UGC

In February 2017, the University Grants Commission (UGC) issued a list of over 38 000 journals (<http://ugc.ac.in/journallist/>) covering a wide variety of fields such as engineering, agriculture, medicine, humanities and social sciences, environment, business and ecology, that it will use to evaluate a researchers' work. Earlier, the Medical Council of India (MCI) vide letter No. MCI-12(1)2015- TEQ/131880 dated 3 September 2015, had defined the norms for what constituted a 'publication' for effecting faculty promotions in medical colleges in India.

The UGC list includes journals covered in Web of Science, Scopus, Indian Citation Index (ICI); journals recommended by the Standing Committee on Notification on Journal and Language Committee; and journals recommended by universities. Based on these publications, researchers in India will be able to earn points that count toward their academic performance indicators, which

will be used in promotion evaluations. These efforts by the MCI and UGC seem to be aimed at standardizing and setting a benchmark for research and allied activities in the field of higher education in India. However, not all are impressed by this move of the UGC. Dr Subbiah Arunachalam, information scientist (DST Centre for Policy Research, Archives and Publication Cell, Indian Institute of Science, Bengaluru) opined, in an email to this correspondent, 'Allocating points to faculty for publishing papers in any one of the 38 000 or so journals, the points depending upon the position of an author in the name order in the byline and basing promotion decision on these points make academic decisions mechanical. Where is the expert evaluation of one's knowledge and skills in all these?'

ALLADI MOHAN, *Tirupati, Andhra Pradesh*

Shortage of doctors in India

There were 988 922 practitioners of western medicine (allopathy) as of 30 June 2016. This is the number of doctors registered with the Medical Council of India and State medical councils. With an estimated population of 1.32 billion, and an assumed 80% availability of doctors, it means that the doctor:population ratio in India is about 1:1668—far less than the WHO recommendation of 1:1000.

To combat this shortage of doctors, the government is considering starting new medical colleges across India. There are, at present, 472 medical colleges. The government also plans to increase postgraduate seats from the current number of about 18 000 by an additional 5000.

SANJAY A. PAI, *Bengaluru, Karnataka*

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