# FORUM FOR MEDICAL ETHICS SOCIETY

Trust registration No. F-17441 (Mumbai), 1995 Society registration No. Mumbai, 218, 1995, GBSD

# Annual Report 2016 - 17

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national bioethics conterence

INDIAN JOURNAL OF MEDICAL ETHICS

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The present Managing Committee was elected at the Annual General Meeting, July 16, 2016. The members elected were:

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### **EXECUTIVE SUMMARY**

We present the Forum for Medical Ethics Society's Annual Report for 2016-17, a year marked by a range of activities targeted at preparations for the Sixth *IJME* National Bioethics Conference (NBC) held in January 2017. Five public engagements on the main conference theme 'Healing and dying with dignity: Ethical issues in palliative and end-of-life care and euthanasia' were undertaken in four cities of Maharashtra - Mumbai, Pune, Nagpur, and Aurangabad from July to November 2016.

Besides this, FMES intervened against the conduct of ReAnima, an unethical clinical trial experimenting on brain-dead persons; submitted a detailed response on the 'International Ethical Guidelines for Biomedical Research involving Human Subjects' of the Council for International Organisations of Medical Sciences (CIOMS); and collaborated in conducting the National Seminar on 'New vaccines for all: Why, Which, When?' from October 20-21, 2016 in New Delhi.

The Sixth NBC was organised by FMES from January 12 to 15, 2017, in Pune, Maharashtra, on the theme 'Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia'. This conference has served as an interactive platform and helped build an active community of those concerned with ethical healthcare and universal access to quality healthcare. Twenty-one organisations collaborated in the Sixth NBC, which was attended by 370 participants from nine countries. Key areas covered by the deliberations were: gender in the context of palliative and end of life care (PC-EoLC), definitional challenges to key terms in PC-EoLC discourse, communication and mediation as a salient component of PC-EoLC and systemic matters. Preceded by 2 pre-conference workshops, the main conference, spread across three days, included 16 parallel sessions for paper presentations, 5 plenaries, 20 workshops and a poster exhibition.

Preparations are currently underway for co-hosting the 14th World Congress of Bioethics & the 7th National Bioethics Conference, from Dec 4-7 2018, on the theme 'Health for all in an unequal world: obligations of global bioethics' jointly with Sama – Resource Group for Women and Health, New Delhi.

The *Indian Journal of Medical Ethics (IJME)* has completed 25 years of continuous publication as the sole independent peer-reviewed bioethics journal published in India. This year, the important target of technical upgradation of the journal was achieved by migrating all 25 years of content to a new website on a WordPress platform. Digital Object Identifiers (DOIs) were acquired for all published articles from 2004 to 2017. Other objectives fulfilled were setting up of a new office, enlarging of human resources with a new full time editorial coordinator, and implementing of the online submission system on the OJS platform. Regular online publication of articles has been achieved. Future plans include building a comprehensive online bioethics repository; extending DOI to all earlier published content from 1993; inclusion in the LinkOut facility of Pubmed for a wider reach.

FMES members continue to serve as guest faculty in research ethics training programmes, as members of Ethics Review Boards, publish extensively both in *IJME* and other important ethics publications, and participate as resource persons at national and international forums.

The report concludes with the audited Financial Report for the year, duly approved by the General Body of the FMES.

### FMES ACTIVITIES 2016-17

### I. Public engagement events

The year 2016-17 was marked by a range of activities preparing for the Sixth *IJME* National Bioethics Conference (NBC). Five public engagements on the main NBC theme 'Healing and dying with dignity: Ethical issues in palliative and end-of-life care and euthanasia' were undertaken in four cities in Maharashtra - Mumbai, Pune, Nagpur, and Aurangabad. These were organised between July 2016 and November 2016, leading up to the main conference in mid-January 2017. These were panel discussions and open public debates to engage with students, lawyers, healthcare providers and specialists from critical care medicine and palliative care, patients and their families. Each event was organised in collaboration with hospitals, academic institutions, and medical associations. Details of these events are available on the NBC website<sup>1</sup>. Over 600 individuals attended these pre-conference meetings.

### II. Collaboration in the National Vaccine Seminar, New Delhi

FMES collaborated with several like-minded organisations to conduct the National Seminar on 'New vaccines for all: Why, Which, When?' on October 20-21, 2016 at the National Documentation Centre Conference Hall, National Institute of Health and Family Welfare, New Delhi. As a wide range of issues on new vaccines and combination vaccines emerged at the National Health Mission's (NHM) Mission Steering Group (MSG) meetings, it was felt that such a seminar would be an opportune platform for robust and wide ranging deliberations. The national seminar sought to facilitate a dialogue on 'New vaccines' in the true spirit of public health and sound scientific quality towards building perspectives and consensus, wherever possible, on important issues. It was successful in mobilising the participation of representatives from the Ministry of Health and Family Welfare, the Indian Council of Medical Research, the World Health Organisation, the Institute of Economic Growth, public health institutions, civil society organisations, academic institutions, medical colleges, hospitals and research institutions. The key outcomes from the seminar deliberations were expected to contribute to future policy level recommendations. These will be further discussed at the International Conference on Vaccines to be organised by the Ministry of Health and Family Welfare in 2017. Some papers developing the key ideas emerging from the seminar were published as part of a special theme issue of *IJME* on "Ethical and legal challenges of vaccines and vaccination"<sup>2</sup>.

### **III. Bioethics training workshops**

### **1**. A perspective building workshop for civil society and non-government organisations working in health and allied themes

This was a one-and a half day workshop from September 19-20, 2016, at the SM Joshi Socialist Foundation, Pune, with about 50 participants. The workshop was organised ahead of the main conference to take the debate to those sections for whom the main event was less accessible. It was conducted in the regional language, Marathi, to reach out to the various groups working in different parts of Maharashtra. The participants found it useful and relevant to their work and said they would like to integrate the issues around palliative and end-of-life care into their own work in their geographical areas of intervention<sup>3</sup>.

### 2. Clinical ethics workshop at Bharati Vidyapeeth, Pune

FMES and Bharati Vidyapeeth University Medical College (BVUMC), Pune, co-organised a day-long workshop titled 'Clinical Ethics Workshop for Faculty of Medical Colleges' on January 16, 2017, at the Bharati Vidyapeeth University Medical College, Pune. Dr Saoji Vivek, Dean, and Dr Shivkumar Iyer, Head, Critical Care Unit, BVUMC, hosted the workshop. Workshop participants came from three medical colleges – BVUMC, B J Medical Government College, and Smt Kashibai Navale Medical College in Pune. About 20 faculty members participated in the workshop.

Dr Aamir Jafarey, Dr Farhat Moazam, Dr Nida Bashir (all from the Centre of Bio-Medical Ethics and Culture, Sindh Institute of Urology and Transplantation, Karachi, Pakistan), Dr Alastair Campbell, Visiting Professor in Medical Ethics and Emeritus Director, Centre for Biomedical Ethics, National University of Singapore, Singapore, served as faculty along with colleagues from India: Olinda Timms, Adjunct Professor, St John's Research Institute, Bengaluru, Karnataka, India; Dr Amar Jesani, Editor-in-Chief, *IJME*, and Dr Sunita VS Bandewar, Secretary, FMES.

<sup>&</sup>lt;sup>1</sup> http://ijme.in/nbc-20140321/index.php/NBC-6/index/pages/view/public-engagement

<sup>&</sup>lt;sup>2</sup> http://ijme.in/articles/ethical-and-legal-challenges-of-vaccines-and-vaccination-reflections/?galley=html

<sup>&</sup>lt;sup>3</sup> Video clips of the sessions and deliberations are available from: http://ijme.in/nbc-20140321/index.php/NBC-6/index/pages/view/s-m-joshi-foundation videos-of-the-event

### 3. Research ethics workshops

3.1 A five-day workshop from April 18-23, 2016, titled 'Research Ethics for Social Science and Public Health Research' was organised by the Tata Institute of Social Sciences (TISS) for its faculty, research scholars and post-graduate students from across different schools within TISS. Dr Amar Jesani was invited to conceptualise and implement the workshop. About thirty five participants including a good number of faculty members actively participated in the workshop. Certificates were issued for completing the course.

FMES members who served as faculty for the workshop were: Dr Amar Jesani, Editor, *IJME*; Dr Sunita VS Bandewar, Independent Researcher, Pune and Working Editor, *IJME*; Prof Srijit Mishra, Director, Nabakrushna Choudhury Centre for Development Studies (ICSSR Research Centre), Bhubaneshwar; Prof Mala Ramanathan, AMCHSS, SCTIMST, Trivandrum; Working Editor, *IJME*.

3.2 A two-day workshop on Jan 23-24, 2017 titled 'Research Ethics for Social Science and Public Health Research' was organised and conducted for the TISS peer community in the same manner as above. About 25 participants took part in the conference.

FMES members who served as faculty for the workshop were: Dr Amar Jesani, Editor, *IJME;* Dr Sunita VS Bandewar, Working Editor, *IJME.* 

### IV. Advocacy and policy level engagement with the Government of India

### 1. Clinical Trial ReAnima: Seeking to halt an unethical trial

The trial entitled 'Non-randomised, open labelled, interventional, single group, proof of concept study with multimodality approach in case of brain death due to traumatic brain injury having diffuse axonal injury' led by Dr H Bansal was registered with the Clinical Trials Registry of India (CTRI)<sup>4</sup>. As per this registration, the aforesaid trial registered on April 29, 2016, as a 'Phase I' trial, proposing to enrol about 20 participants with a diagnosis of brain death, had already started and the trial would continue for a period of three months, in which brain-dead patients would be involved in the experiment for a period of 15 days. It was an international collaboration between Bioquark Inc, USA<sup>5</sup>, a private entity and Revita Life Sciences<sup>6</sup>, India, owned by Dr H Bansal who served as the Principal Investigator for this project. The experiment involved isolating the stem cells from the brain dead patient, injecting the stem cells through the lumbar cerebral spinal fluid into the brain, conducting median nerve stimulation, laser stimulation and the use of some drugs in order to revive the brain dead patient.

FMES submitted detailed substantive letters to register requests-cum-complaints about this trial which was in violation of the concerned regulatory frameworks, biomedical research ethics principles, and medical ethics code of the Medical Council of India with six concerned authorities namely: (a) the Registrar, Medical Council of Uttarakhand; (b) the Registrar, the Medical Council of India, New Delhi; (c) the Director General, Indian Council of Medical Research, New Delhi; (d) The Drugs Controller General of India, Central Drugs Standard Control Organization, Directorate General of Health Services, Ministry of Health and Family Welfare, GoI; (e) The Member Secretary, National Apex Committee for Stem Cell Research and Therapy, India Secretariat, ICMR Headquarters, New Delhi; and (f) Director, National Organ & Tissue Transplant Organisation, New Delhi, India.

An editorial<sup>7</sup> by Sandhya Srinivasan and Veena Johari was published in JJME (July-Oct 2016) on this trial raising a number of concerns that also featured in the letters of complaint sent to the concerned government authorities. The trial was eventually de-registered from CTRI.

Contributors: Adv Veena Johari, Dr Sunita VS Bandewar, Dr Sanjay Nagral, and Dr Amar Jesani.

### 2. Comment on EoLC Bill to the Ministry

A draft bill titled "The Medical Treatment of Terminally III Patients (Protection of Patients and Medical Practitioners) Bill" was placed in the public domain by the Government of India (GoI) seeking comments from the public at large. The draft bill draws upon reports by two Law Commissions of India, that is the 196th (2006) and 241st (2012) and the debate that was generated by the public interest litigation filed by Pinki Virani in relation to the case of Aruna Shanbaug in March 2011, followed by the Supreme Court's judgment on the same allowing passive euthanasia in certain situations.

<sup>&</sup>lt;sup>4</sup> http://ctri.nic.in/Clinicaltrials/pubview2.php

<sup>&</sup>lt;sup>5</sup> http://www.bioquark.com/

<sup>6</sup> http://revitalife.co.in/

<sup>&</sup>lt;sup>7</sup> Available at: http://ijme.in/articles/response-to-proposed-research-to-reverse-brain-death-more-than-regulatory-failure/?galley=html

FMES submitted a detailed critical comment<sup>8</sup> on the aforementioned draft bill to the GoI. The comment was premised on the principle of honouring death that maintains human dignity and upholds the individual's right to life (increasingly also bearing an interpretation of right to die with dignity) and liberty that is conferred by Article 21 of the Constitution of India and Article 4 of the Universal Declaration of Human Rights. The general recommendations from FMES mentioned that the bill should include a preamble locating the bill in the broader ethical and medical debate which covers various dimensions - of the issue at hand and ought to cover the foundational principles of the proposed bill, the human rights framework, the framework of the Indian Constitution and an ethics framework. A number of gaps, constraints and internal contradictions were pointed out for a revised bill to be brought back to the public for wider consultation.

Contributors: Dr Sunita VS Bandewar and Dr Sanjay Nagral

### V. Advocacy and policy level engagement with international entities

### **1**. Comment on the revised Ethics Guidelines of the Council for International Organisations of Medical Sciences (CIOMS)

Advancements in the domain of research on human subjects have intensified the need to have standard guidelines which are internationally followed for ensuring transparency in research, ascertaining the rights and responsibilities of both the subjects of research and researchers, and for ensuring that systematic, valid and ethical research is conducted. Against this backdrop, the Executive Committee of CIOMS decided to revise the CIOMS Ethical Guidelines for Biomedical Research Involving Human Subjects so as to include and address the recent changes and questions. The Working Group duly broadened the area of focus from "biomedical research" to "health-related research", while asserting that the ethics of social science research, behavioural studies, public health surveillance and other research activities are not discrete, but inform each other. As the CIOMS website explains, the present scope of the guidelines includes all manner of health-related research with humans, including observational research, clinical trials, biobanking and epidemiological studies. In response to the call for public comments, the FMES submitted a detailed response to the CIOMS International Ethical Guidelines for Biomedical Research involving Human Subjects. From the list of 25 guidelines, the FMES team (comprising Sarojini N, Sunita VS Bandewar and Vijayaprasad Gopichandran) engaged critically and in depth with nine guidelines as follows:

- Guideline no 7: Community engagement
- Guideline no 8: Collaborative partnership and capacity building for research and review
- Guideline no 15: Research involving vulnerable persons
- Guideline no 17: Research involving children and adolescents
- Guideline no 18: Women as research participants
- Guideline no 19: Pregnant women and lactating women as research participants
- Guideline no 20: Research in disaster situations
- Guideline no 21: Implementation research
- Guideline no 22: Use of online information or tools in health related research

The revised guidelines, incorporating the comments, have now been published on the CIOMS website<sup>9</sup>.

Contributors: Dr Rakhi Ghoshal, Dr Vijayaprasad Gopichandran, Dr Sunita VS Bandewar, Dr Sanjay Nagral, Ms Sarojini N B, Dr Mala Ramanathan

### **VI. Publications**

### 1. Organ transplantation: Compassion and commerce (Selected readings from IJME)

To commemorate the start of the 25th year of the journal, FMES published an anthology of selected articles from the *IJME* on organ transplantation, in January 2017. The huge supply-demand deficit in available organs has contributed to making organ transplantation an ethical minefield for medical professionals, which stimulates regular heated debates. The global ethics community and *IJME* have engaged with this issue right from the inception of the journal. Today the challenges are only assuming new forms, so it seemed an opportune time to put together such an anthology constituting a rich and critical contribution to the ethics discourse around organ transplantation. The anthology also reflects the growth of *IJME* from a small newsletter to an academically robust journal. It is imperative that the debate continues, and this little book, which was released at the Sixth NBC, may contribute to it in a small way.

<sup>&</sup>lt;sup>8</sup> Available at: http://ijme.in/pdf/the-medical-treatment-for-terminally-ill-patients.pdf

<sup>&</sup>lt;sup>9</sup> http://www.cioms.ch/index.php/12-newsflash/400-cioms-inernational-ethical-guidelines

### NATIONAL BIOETHICS CONFERENCES

Since the year 2005, the FMEs has regularly organised the *IJME* National Bioethics Conferences (NBC), providing an inclusive and interactive platform for all participants in healthcare, health research, health activists, lawyers and policy makers to come together and share experiences, debate and exchange ideas on the relevant ethical issues. The Sixth NBC was held in January 2017 in Pune, Maharashtra, on the theme "Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia". This interactive platform has helped build up a community of those interested in ethical healthcare and access to quality healthcare for all sections of people. Each NBC has been held in a different part of the country so as to involve individuals and groups from those regions in participating. Those presenting papers at the NBCs are invited to submit them to be considered for publication in *IJME* after peer review. Participants come from several countries and this year we had participants from Pakistan, Sri Lanka, the United Kingdom, Canada, Singapore, the United States of America, Australia, Switzerland and India.

		THE NATIONAL BIOETI	HICS CONFERENC	ES (NBC)				
NO.	YEAR	THEME	VENUE	NO. OF COLLABORATING ORGANISATIONS	NO. OF PARTICIPANTS			
1	2005	Ethical challenges in biomedical and social science research	Mumbai	20	317			
2.	2007	Moral/ethical imperatives of healthcare technologies	NIMHANS, Bengaluru	38	500			
3.	2010	Governance in healthcare	AIIMS, New Delhi	38	350			
4.	2012	Ethics and regulatory challenges in health research	University of Hyderabad, Hyderabad	03	370			
5.	5. 2014 Integrity in healthcare and research		St John's Medical College, Bengaluru	03	695			
6.	6. 2017 Healing and dying with dignity: ethical issues in palliative care, end-of-life care and euthanasia		YASHADA, Pune	21	370			
*All deta	*All details of past National Bioethics Conferences are available on the IJME website							

### The Sixth National Bioethics Conference: An Overview

The *IJME* Sixth National Bioethics Conference (6th NBC), themed, "Healing and dying with dignity: ethical issues in palliative care, end-of-life care and euthanasia", was held in Pune, Maharashtra from January 12–15, 2017. Palliative care (PC) and end-of-life care (EoLC) are areas of concern that have been largely neglected. The theme of euthanasia was inspired partly by the debates surrounding the case of Aruna Shanbaug, who died after spending more than four decades in a persistent vegetative state after being sexually assaulted while on nursing duty at a government hospital in Mumbai. Further, euthanasia had been identified as a "gap in discussion" at the 5th National Bioethics Conference, 2014. The 6th NBC aimed to inform policy on end-of-life care, and consolidate processes for the reform of the legal and health systems in India.

The 6th NBC was co-organised by the Forum for Medical Ethics Society (FMES), *Indian Journal of Medical Ethics (IJME)* and Mahila Sarvangeen Utkarsh Mandal (MASUM), along with 20 other collaborating organisations. The conference comprised six plenaries, 16 parallel tracks (during which about 60 papers were presented), 20 workshops and 16 poster presentations.

### Participation

The 370 participants came from Australia, Canada, Pakistan, Singapore, Sri Lanka, Switzerland, the United Kingdom, the United States of America, and 15 states across India. They included doctors, medical students, social scientists, academics, bioethicists, counsellors, economists, lawyers, philosophers, journalists, students, theologians, community workers, researchers, advocacy organisations, administrators and international organisations.

Two pre-conference workshops were held, namely "Transitions of care in patients with advanced illnesses" and "Gender justice – towards a comprehensive response to an inter-sectoral dialogue on gender-based violence". A workshop in the regional language and five public debates across four cities in Maharashtra were organised in the run-up to the main event. These events helped expand the scope and reach of the debates at the main conference and reached out to another 700 participants. These events were organised in collaboration with academic institutions, medical professional societies and hospitals.

Some of the key issues discussed around the themes of the NBC were:

- understanding palliative care in the context of class, caste, gender and sexuality;
- the adverse burden on women as caregivers is an outcome of structural factors, and their position as care receivers;
- strategies to enhance provider communication with patients and their relatives
- accentuated discrimination faced by transgenders, and the LGBT community in PC/EoLC;
- challenges faced by care givers regarding disclosure, medical error and increasing violence against them;
- dilemmas in organ donation and allocation;
- the mental health of persons at the end of life or diagnosed with terminal illness, that of their caregivers, and medical staff;
- the need to re-examine critical terms in the PC/EoLC discourse;
- the overarching issue of making universal access to healthcare a reality in India, and facilitating advocacy and legal reforms.

The full text of the report is available online on the *IJME* website<sup>10</sup>. More resources such as video recordings of plenaries, workshop, and public events are available from the Sixth NBC website<sup>11</sup>.

### **Conference Collaborators**

- 1. Anveshi Research Centre for Women's Studies, Hyderabad, Telangana, India. www.anveshi.org.in/
- 2. CanSupport, New Delhi, India. www.cansupport.org/
- 3. Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai. MH, India. www.cehat.org, www.gme-cehat. org and www.patientsrights.in
- 4. Centre for Ethics, Yenepoya University, Mangaluru, Karnataka, India. http://yenepoya.edu.in/colleges. php?id=41&org=center/
- 5. Centre for Health and Social Justice (CHSJ), New Delhi, India. http://www.chsj.org/
- 6. Cipla Palliative Care & Training Centre, Pune, MH, India. http://www.carebeyondcure.org/
- 7. The Department of Critical Care Medicine, BharatiVidyapeeth University Medical College, Pune, MH, India. http://mcpune.bharatividyapeeth.edu/SiteData/pdf/Medical/CriticalCare.pdf
- 8. FIAMC Biomedical Ethics Center, Mumbai, MH, India. www.fiamc.org
- 9. HALO Medical Foundation (HMF), Osmanabad, MH, India. http://www.halomedicalfoundation.org/
- 10. Jnana-DeepaVidyapeeth (JDV), Pune, MH, India. www.jdv.edu.in/
- 11. MOHAN (Multi Organ Harvesting Aid Network) Foundation, Chennai, TN, India. www.mohanfoundation.org/
- 12. Network for Promotion of Ethics in Medicine, Kolkata, West Bengal
- 13. Observer Research Foundation (ORF) Mumbai, MH, India. www.orfonline.org/
- 14. Sama Women's Health, New Delhi www.samawomenshealth.org
- 15. Simpatico Palliative Connect, Pune, MH, India. www.simpaticopalliative.org/
- 16. Sri Chitra Tirunal Insitute of Medical Sciences and Technology, Thiruvananthapuram, Kerala, India https://www.sctimst.ac.in/
- 17. St John's Medical College and Hospital, Bengaluru, Karnataka, India. www.stjohns.in/
- 18. University of Hyderabad and the Institutional Ethics Committee, Hyderabad, Telangana, India www.uohyd.ac.in/
- 19. Vidhayak Trust, Pune, MH, India.
- 20. YR Gaitonde Medical, Educational and Research Foundation (YRGCARE), Chennai, TN, India www.yrgcare.org/
- 21. Zonal Transplant Coordination Center (ZTCC), Pune, MH, India www.ztccpune.com

<sup>&</sup>lt;sup>10</sup> Available at: https://ijme.in/articles/ethical-issues-in-death-dying-and-palliation-the-ijme-sixth-national-bioethics-conference/?galley=html

<sup>&</sup>lt;sup>11</sup> http://ijme.in/nbc-20140321/index.php/NBC-6/index/pages/view/nbc6-home

### Funders

The organisers are grateful to the funders who supported the conference: Indian Council for Medical Research, New Delhi, India; Cipla Foundation, Mumbai, India; Narotam Sekhsaria Foundation, Mumbai, India. Thanks are also due to Wellcome Trust, London, UK, for a grant to MASUM towards organising the NBC.

### Looking Ahead: World Conference of Bioethics 2018

### **Co-hosting the 14th World Congress of Bioethics, 2018**

The International Association of Bioethics (IAB) has been organising biennial international conferences in bioethics since 1992. Past Congresses have been held in Mexico City (2014), Rotterdam (2012), Singapore (2010), Croatia (2008), China (2006), Australia (2004), Brazil (2002), the United Kingdom (2000), Japan (1998), the United States (1996), Argentina (1994), and Amsterdam (1992). The 13th World Congress of Bioethics was held in Edinburgh in June, 2016 (http://iab2016.com/).

In 2015, the IAB invited proposals from interested organisations across the globe to co-host the 14th World Congress of Bioethics. The overarching theme of the 14th WCB will be 'Health for all in an unequal world: obligations of global bioethics'. This theme was chosen against the backdrop of colossal inequities in health and healthcare. Despite gains in health research, and new discoveries in healthcare, the global community is far from achieving equitable healthcare systems so far. Situating the WCB in the developing world was intended to provide scope for raising philosophical and political issues related to the developing world and its relationship with the developed countries. FMES-*IJME*, jointly with Sama – Resource Group for Women and Health (http://www.samawomenshealth.org/), won the bid to host the 14th WCB, which will be contiguous with the 7th NBC and will be held in New Delhi from December 4-7, 2018. Preparations for this important international event are ongoing.

### INDIAN JOURNAL OF MEDICAL ETHICS (IJME)

### Milestones in the journal's development during the year 2016-17

**Website migration:** *IJME* has migrated to a new website on a WordPress platform. All articles published over 25 years have successfully been transferred to the new platform, while retaining OJS for the back end to streamline the article submission process. There were several hiccups at the initial stages, most of which have now been resolved. Indexing has not been disturbed; but the website saw a steep fall in usage data beginning in November, 2016. This was also linked to *IJME*'s non-appearance on Google Search. The web team has been struggling with this serious problem and has resolved it after re-submitting all the data to Google. By March 8, the website had been restored on Google and appeared at the top of its search engine results. After publication of the April-June issue of *IJME*, the usage figures showed improvement, and we need to ensure that this improvement leads to steady growth over the next few months.

The Home Page has also been re-organised for a more convenient and user-friendly reading experience.

**Digital Object Identifier:** DOI is a unique alphanumeric string assigned by a registration agency to identify content and provide a permanent link to its location on the Internet. It was decided to apply for DOI through our website managers, Z-Aksys, for all articles published in *IJME* from 2004 onwards. The process began from March 20 and was completed by end- April for all published articles from 2004 to 2016, retrospectively. DOI will be obtained for future *IJME* articles, and the period prior to 2004 will be covered as soon as funds permit.

**Online submission system via the OJS platform:** An important pending goal has been the operationalisation of the automatic submission system. The use of this automatic system will ensure transparency, and facilitate analysis of the material received and published. With an additional full-time Editorial Coordinator taking charge, we have been testing the system regularly and it has been found adequate. It has become operational for internal functioning and review starting April 1, 2017. The next stage will be to open the system to the public, once it has been made completely compatible with our needs.

**The BMJ Award:** IJME competed in the category "Recognition for promoting integrity/transparency in healthcare" under the direction of Dr Sanjay Nagral. This was the journal's first attempt in such a competition, and we reached the third and final round of the prestigious contest, which is quite encouraging.

**Registration** of the journal with the Registrar of Newspapers for India, which had been pending over several years, was completed in 2016.

#### What we published in 2016-17

Submissions received in 2016-17: From April 1, 2016 to March 31, 2017, we received 182 submissions. Of these 72 were published, 73 rejected, 08 are currently under review, 2 were withdrawn by the authors, while 12 are with the authors for revision, and 15 have been accepted and are awaiting publication.

Through 2016-17, *IJME* has published a total of 92 submissions in four issues as well as online, ahead of print. Some of these were carried over from the previous year. The published pieces consisted of 5 Editorials, 16 Articles, 24 Comments, 3 Case studies, 4 Commentaries, 3 Reports, 13 Letters, 13 Book and film reviews, 7 items under Discussions, and 2 each under Reflections and Creative Space.

### **Our contributors**

AFFILIATIONS OF AUTHORS IN 2016-17							
Occupational Apr-June 2016		Jul-Sep 2016	Oct-Dec 2016	Jan-Mar 2017			
Health care	30	23	25	19			
Health NGOs	01	04	02	05			
Social sciences	06	07	05	02			
Law		01	02				
Students	03						
Journalism		02	01				
TOTAL	40	37	35	26			
India	30	30	27	14			
Oher countries	10	07	08	12			

#### **Our reviewers**

The standards that the journal aspires to maintain are substantially supported by our reviewers with the dedicated work they put into assessing and improving submissions. Besides internal reviewers, the following external reviewers supported *IJME* in the year 2016-17:

Alastair V Campbell, Alok Sarin, Amit Sengupta, Anagha Tambe, Anant Phadke, Anne Mattam, Anindita Majumdar, Anoop Thekkuveetil, Anuradha Rose, Bishakha Datta, C Priyadarshini, Chinu Srinivasan, Dominique Martin, Faisal Khan, Florencia Luna, George Thomas, Jaya Sagade, Kavita Bhatia, Malu Mohan, Manjulika Vaz, Mario Vaz, Mohan Rao, Molly Jacob, Monica Sakhrani, Muthu Pratibha, Nikhil Govind, Peter Doshi, Peush Sahni, GD Ravindran, Jacob Leveridge, Jacqueline Chin Joon Lin, Jayanta Bhattacharya, Joe Varghese, Joy Akoijam, Lopa Mehta, Olinda Timms, PS Rakesh, Priya Satalkar, RS Rajan, Raffaella Ravinetto, Rajib Dasgupta, Rajkumar Lenin, Raman Kutty, Ravindra Ghooi, Ravi Prasad Varma, Samrat Sinha, Sangeeta Rege, Sanjiv Lewin, Sanish Davis, Santosh K Chaturvedi, Santosh Karmarkar, Santhosh Kumar, Shubha Ranganathan, Shyamala Nataraj, Shinjini Mondal, Siddharth David, Silke Schicktanz, SK Godwin, Soumitra Datta, Subrata Mukherjee, Sudarshini Subramaniam, Sumit Kane, Sundar Sarukkai, Sunu Thomas, Tom Jefferson, Udaya Mishra, Uma Santhosh, Valerie Luyckx, Varalakshmi Elango, Varsha Ayyar, Veena Johari, Vidya Satyanarayanan, Vina Vaswani, William Joe, Yashashri Shetty, Y Madhavi, Zamrooda Khanday, Zile Singh.

### Social media presence

The *IJME* Facebook group now has 7321 members. This is an increase of about 27% from 5771 in March 2016. Bioethics news and new articles published in *IJME* are regularly posted on the Facebook page and usually give rise to interactive discussion.

The print issue of the journal goes out to around 400 subscribers and supporters. It has been an expensive undertaking, but the number of subscribers, especially institutions, seems to be increasing. Hence it has been decided to continue with the print edition in the interests of reaching as many readers as possible.

### **Editorial Board**

The Editorial Board of *IJME* consists of eminent and scholarly clinicians, researchers and healthcare activists. They are active contributors to this journal whether as authors, reviewers and offer their generous guidance whenever necessary. The Editorial Board member details for 2016-17 are available on the *IJME* website.

### Changes in the editorial office

**New Editorial Coordinator:** With a new Editorial Coordinator joining the journal from October 2016, a long felt need has been met and this has improved efficiency. Initially, both editorial coordinators worked full time; but from May 2017, one has moved to part time work. With two editorial staff members, several pending goals listed above are close to completion. These include streamlining of the website, making the OJS submission system operational, and acquiring DOIs for all published journal content from 2005.

**New office:** During the previous year, *IJME* was using rented premises at Bandra East which imposed a substantial financial burden on the organisation. Subsequently, we received a generous offer to use, free of charge, the Nagral Clinic in Prabhadevi, a more central location, which was accepted. We occupied the clinic for about four months. From February 2017, FMES/*IJME* has finally got its own compact and convenient office at Prabhadevi at a reasonable rent. Some basic furniture has been purchased, and the office is now fully operational.

#### **Immediate goals**

- 1. Building a repository for all matters relevant to bioethics and medical ethics, including links to research, laws and policy documents, conferences national and international, to websites of like-minded organisations working with similar goals is the next target. This would require substantial funding, so for now, the plan is to upload relevant matter already available with us, as a beginning.
- 2. Extending DOI to all of our published content from 1993 onwards.
- 3. Inclusion in PubMed's LinkOut scheme which will provide direct access to readers from the PubMed database to articles on our website, leading to a substantial increase in *IJME*'s reach.

## FMES CONTRIBUTIONS TO THE BIOETHICS DISCOURSE (2016-17)

#### A: Guest faculty in research ethics training programmes

**Amar Jesani:** June 9, 2016: Conducted a session on "Research ethics" at the Summer School on "Health Policy Research: Theory and Applications" organised by Azim Premji University and Indian Health Economics and Policy Association, in Bangalore;

**Amar Jesani:** August13-16, 2016: As a visiting professor, conducted training of the students of Masters in Healthcare Management for their module, "Health, Society and Ethics" (0.5 credit course module, including assessment of 50 students), at the Indian School of Business, Hyderabad;

**Amar Jesani:** October 14, 2016: Conducted a session on "Medical ethics, gender and abortion" in the two-day training institute for students at the Grant Medical College, JJ Group of Hospitals, Mumbai;

**Amar Jesani:** November 26, 2016: Conducted a session on "Ethical issues in social science research"; at the Modular Training Workshop for students enrolled in the direct PhD program at TISS, Mumbai;

**Amar Jesani:** February11, 2017: Conducted a session on "Communication and informed consent in health care" at the Goa Medical College as part of the program of Difficult Dialogues, organised by the University College, London, on 11-12 February 2017 in Goa;

**Amar Jesan**i: March 2, 2017: Conducted session on "Ethics of abortion and conscientious objection", at the Youth Refresher Institute of the Asia Safe Abortion Partnership, in Bangkok, Thailand;

**Amar Jesani (with Mala Ramanathan):** April 25-29, 2016: The "Public Health and Research Ethics" course for students in the Post Graduate Diploma of Biomedical Ethics (PGD) Class of 2016, and Master in Bioethics (MBE) Class of 2017 programmes, at the Centre of Biomedical Ethics and Culture (CBEC), of the Sindh Institute of Urology and Transplantation (SIUT), Karachi, Pakistan;

**Amar Jesani (with Mala Ramanathan):** May 23 to 27, 2016- Conducted a "Five Day Intensive Short Training Course in Ethics Issues in Biomedical Research", organised by the Centre for Ethics, Yenepoya University, Mangalore, India;

**Shyamala Nataraj:** March 2017 - Spoke on "Sensitisation on Research ethics for Sex workers and Transgenders", National Network for Sex Workers & Alternate Law Forum;

**Shyamala Nataraj:** September 2016 - "Ethical considerations for para medical professionals": SRM Medical College and University;

**Sunita VS Bandewar:** Five day workshop between April 18 and 23, 2016 titled 'Research Ethics for Social Science and Public Health Research' was organized by the Tata Institute of Social Sciences (TISS) for its faculty [Faculty];

**Sunita VS Bandewar:** September 19-20, 2016 - Perspective building workshop for civil society and non-government organizations working in health and allied themes on palliative care, end-of-life care and euthanasia [the S M Joshi Socialist Foundation, Pune, MH, India]. [Part of the organizing group and resource person];

**Sunita VS Bandewar:** November 27-28, 2016 - WHO & SAFETYNET Workshop on Ethics of Epidemics, Research and Surveillance at Siem Reap, Cambodia, [Faculty];

**Sunita VS Bandewar:** January 16, 2017- One day workshop titled "Clinical Ethics Workshop for Faculty of Medical Colleges" at the Bharati Vidyapeeth University Medical College, Pune. [Lead organiser on behalf of FMES, and faculty];

**Sunita VS Bandewar:** January 23 - 24, 2017 – Organised and conducted Two day workshop titled "Research Ethics for Social Science and Public Health Research" for the TISS peer community [Faculty];

**Vijayaprasad Gopichandran:** February 11, 2016 - Served as guest faculty for Public Health Ethics training for MPH scholars at the National Institute of Epidemiology, ICMR, Chennai;

**Vijayaprasad Gopichandran:** April 22, 2017 - Was on the guest faculty for Public Health Ethics training for MPH scholars at the School of Public Health, SRM University, Kancheepuram.

### B: Members of committees appointed by the Government of India and allied bodies

**Shyamala Nataraj:** January 2016 till date - Executive Committee Member, Tamil Nadu State AIDS Control Society (TANSACS);

**Sunita VS Bandewar:** March 2017 -Member of the group constituted by the Indian Council of Medical Research for brainstorming key terms and concepts relating to palliative care, end-of-life care and euthanasia ;

**Sunita Simon Kurpad:** Served as co-Chair of the Boundary Guidelines Task Force of the Indian Psychiatric Society (IPS), instrumental in drafting Guidelines for doctors on Sexual Boundaries in the doctor patient relationship, binding on all member psychiatrists;

**Sunita Simon Kurpad:** Serves as current Chair of the Boundary Guidelines Task Force of the IPS and working on Nonsexual Boundary Guidelines in the doctor patient relationship;

**Vijayaprasad Gopichandran:** Served as Member of Advisory Group for development of curriculum for online course on research ethics for members of institutional review boards and ethics committees set up by the National Institute of Epidemiology, ICMR in collaboration with the World Health Organisation.

### **C: Members of Ethics Review Boards**

Amar Jesani: Member, Institutional Review Board, TISS, Mumbai;

Amar Jesani: Member, Research Ethics Board, Medecins Sans Frontieres;

Amar Jesani: Member, Central Ethics Committee, ICMR, Delhi;

Barun Mukhopadhyay: Chairperson, Institutional Ethics Committee, National Institute of Biomedical Genomics, Kalyani, India;

**Barun Mukhopadhyay:** Member, Institutional Ethics Committee, Anthropological Survey of India, Kolkata, Indian Statistical Institute, Kolkata;

Barun Mukhopadhyay: Member, Institutional Ethics Committee, Indian Statistical Institute, Kolkata, India;

**Leni Chaudhuri:** Member Secretary, Joint Ethics committee of Narotam Sekhsaria Foundation and Salaam Bombay Foundation;

Leni Chaudhuri: Member- Institutional Review Board of Prince Aly Khan Hospital, Aga Khan Health Services;

Leni Chaudhuri: Member- Institutional Ethics Committee, Maniben Nanavati College, SNDT Women's University.

Lubna Duggal: Member, Institutional Ethics Committee in Research at Maniben Nanavati Women's College, Mumbai.

Mala Ramanathan: April 2013 till date - Member, IEC, IIT Gandhinagar;

Mala Ramanathan: June 2014 till date - Member Secretary of Sri Chitra TIMST-IEC;

Mala Ramanathan: 2014 till date - Member, IEC, HAP, Thiruvananthapuram;

Sanjay A Pai: July 2009 till date - Member, ICMR Regional Occupational Health Centre, Bengaluru;

Sanjay A Pai: 2010-16 - Member, IRB, Columbia Asia Hospitals, India;

Sanjay A Pai: 2012 till date - Chairman, Institute of Ayurveda and Integrative Medicine [FRLHT] Bengaluru;

Sanjay A Pai: 2012-16 - Member, Hindustan Unilever Independent Ethics committee, Bengaluru; 2016 till date – Chairman;

Sanjay A Pai: 2013-16 - Chairperson, NU Trust Hospitals, Bengaluru;

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Sanjay A Pai: 2015 till date - Member, IRB, Karunashraya Hospice, Bengaluru;

Sanjay A Pai: 2016 till date – Member, National Centre for Disease Information and Research (ICMR) National Cancer Registry Programme, Bengaluru

**Shyamala Nataraj:** June 2014 till date - Member, Institutional Ethics Committee, National Institute for Research in Tuberculosis (NIRT);

**Sunita VS Bandewar:** December 2016 till date - Institutional Ethics Committee, Vishwanand Kendra Centre for Integrative Medicine And Research, Pune;

**Sunita VS Bandewar:** June 2013 till date -Member, Foundation for Research and Community Health (FRCH), Pune-Mumbai, MH, India;

**Sunita VS Bandewar:** November 2006 till date - Member, International Ethics Review Board for Medecins Sans Frontieres, Geneva, Switzerland;

Vijayaprasad Gopichandran: Member, Ethics Committee of School of Public Health, SRM University

#### D: Participation in workshops, seminars, conferences, colloquiums, international visits

**Amar Jesani:** April 01, 2016 - The research ethics workshop organised by the Institutional Ethics Committee of the School of Medical Sciences and Public Health, Central University of Hyderabad, India. Conducted the session on "Research bioethics: History, principles and guidelines";

**Amar Jesani:** April 04-05, 2016 - Presentation titled, (En)countering invisible disasters and (Un)Ethics of inequities" in the session titled Silent Disasters, in the Roundtable organised by the Jamshetji Tata School of Disaster Studies, at the TISS, Mumbai;

**Amar Jesani:** April 14, 2016 - Moderated a session on "Compensation in Clinical Trials" in the National Seminar on the "Access to medicine and compensation in clinical trials", organised by Sama: Resource Group for Women and Health at Indian International Centre, New Delhi;

**Amar Jesani:** October 19, 2016 - World Bioethics Day: Delivered public lecture on "Bioethics and human rights: Conflict, deliberation and confluence of two approaches". At the public celebration meeting organised by the TNMC-UNESCO -MUHS Bioethics Unit at the TN Medical College and BYL Nair Hospital, Mumbai;

**Amar Jesani:** November 4, 2016 - Presentation on "Justice in clinical research: Deliberation on dumping, exploitation and integrity", at the 4th National Conference and International Colloquium of the Forum for Ethics Review Committees in India", at the Jadavpur University. Kolkata;

**Amar Jesani:** December11, 2016 - Delivered key-note talk titled "The ethical imperative of transparency in clinical research: Obligations of research regulators, scientists and journals", at the 2nd IIMA International Conference on Advances in Healthcare Management Services, at the Indian Institute of Management, Ahmedabad;

**Amar Jesani:** December 14, 2016 - Participated in the ICMR-WHO national consultation on "National Ethical guidelines for Biomedical and Health Research Involving Human Participants", at the ICMR, Delhi;

**Amar Jesani:** February 25, 2017 - Delivered a key-note address on "Reproductive health ethics: Surrogacy, the ultimate controversy?" at the 1st National Bioethics and Medical Research Conference (ETHOS 2017), organised at the Mahatma Gandhi Institute of Medical Sciences, Sevagram, Wardha from 24 to 26 February 2017;

**Amar Jesani (with Mala Ramanathan, Sunita VS Bandewar):** April 18-22, 2016 - The five-day intensive training workshop for faculty and doctoral students on the 'Research Ethics for Social Science and Public Health Research', Organised by the Tata Institute of Social Sciences, Mumbai, India;

**Amar Jesani (with Sunita VS Bandewar, Rakhi Ghoshal, Subrata Chattopadhyay and Olinda Timms):** September 24, 2016 - One day training workshop, titled "Medical ethics training" for medical students and faculty of the BR Ambedkar Medical College and Hospital, and public health staff, organised by the State Health System Resource Centre, Raipur, Chattisgarh;

**Amar Jesani:** January 16, 2017 - Conducted a session on "Physicians in dual role: As instrument od state in interrogation") at One day Clinical Ethics Workshop organised by the FMES for the Faculty of Medical Colleges in Pune (Post-Sixth NBC Event), at Bharati Hospital and Research Centre, Bharti Vidyapeeth University Medical College Campus, Pune ;

**Amar Jesani (with Sunita VS Bandewar):** January 23-24, 2017- Conducted a two day workshop for the faculty and researchers on "Research ethics for social science and public health research", at the TISS, Mumbai;

**Barun Mukhopadhyay (with Soumitra S Datta and Subrata Chattopadhyay):** January 14, 2017. Conducted a workshop on Advanced cancer care: Ethics of communication preferences of patients, their carers, clinicians and society at the Sixth NBC, Pune;

**Mala Ramanathan:** June 15-17, 2016 - Presented a poster at the International Association of Bioethics (IAB) Conference, Edinburgh, titled "The Non-Communicable Disease Programme in Kerala State, no treatment vs state sponsored ineffective treatment" jointly with Raviprasad Varma;

**Mala Ramanathan:** November 3-4 2016 - Presented a case study titled 'Exclusion of married adolescents in a study of gestational diabetes mellitus, at the Global Forum for Bioethics in Research, Meeting on Ethics of Research in Pregnancy, Buenos Aires, jointly with K Sakeena;

**Rakhi Ghoshal:** January 13-15, 2017- Presented a paper titled 'Contingent-caregivers and acrimonious-care: care giving in a public hospital maternity ward', at the 6th National Bioethics Conference, Pune, India;

**Rakhi Ghoshal:** October 20-21, 2016 - Attended the two-day, national seminar titled 'New Vaccines for All: Why, Which, When', organized by Sama, Resource Group for Women and Health, Jan Swasthya Sahyog (JSS), National Medical Journal of India (NMJI) and Forum for Medical Ethics Society (FMES) at New Delhi;

Sandhya Srinivasan: February 24-26, 2017- Presentation on the cervical cancer screening trials at The First National Bioethics, Medical, and Research Conference, Mahatma Gandhi Institute of Medical Sciences, Sevagram, Maharashtra;

**Shyamala Nataraj:** February 2017 - Served as Chair, Panel on Ethics in Health Research, National Consultative Meet on ICMR Draft National Ethical Guidelines for Biomedical and Health Research involving Human Participants, IERB, Jawaharlal Nehru University, New Delhi;

**Sunita VS Bandewar:** January 12-15, 2017 - Member, Conference Organising Committee, Sixth National Bioethics Conference co-hosted by FMES-IJME and MASUM, Pune, MH, India;

**Sunita VS Bandewar:** January 12, 2017-Jointly conceptualised and organised a pre-conference titled 'An intersectoral engagement workshop Enhancing Quality of Response of the System to Survivors of Gender Based Violence: A systemic Ethical Obligation towards Gender Justice' at the Sixth National Bioethics Conference, Pune, MH, India;

**Sunita VS Bandewar:** January 12-15, 2017 - Panelist for a workshop titled 'The Marginalised in Palliative Care' at the Sixth National Bioethics Conference co-hosted by FMES-IJME and MASUM, Pune, MH, India;

**Sunita VS Bandewar:** November 27-28, 2016 - WHO & SAFETYNET Workshop on Ethics of Epidemics, Research and Surveillance at Siem Reap, Cambodia, [Faculty];

**Sunita VS Bandewar:** November 19, 2016 - Gave a talk on the occasion of International Bioethics Day for faculty and students titled 'Importance of bioethics to medical profession' at Dhondumama Sathe Homoeopathic Medical College, Karve Road, Pune, MH, India;

**Sunita VS Bandewar:** October 22, 2016 - Speaker, at the public event on 'Healing and dying with dignity: Debating palliative and end-of-life care' co-hosted by the ISCCM, Aurangabad chapter and the organisers of the Sixth NBC, by at the Indian Medical Association Hall, Adalat Rd, Aurangabad, MH, India;

**Sunita VS Bandewar:** November 4-5, 2016 - Plenary Speaker at The 4th National Conference of Forum for Ethics Review Committees in India & International Colloquium (FERCICon2016), Dr Triguna Sen Auditorium, Jadavpur University, Kolkata, West Bengal, India.;

**Sunita VS Bandewar:** September 2016 - Attended Annual meeting of the International Ethics Review Board for Medecins Sans Frontieres, Geneva, Switzerland in Barcelona, Spain;

**Sunita VS Bandewar:** September 2, 2016 - Speaker at public event titled 'Healing and dying with dignity: Debating palliative and end-of-life care' co-hosted by Dept of Philosophy and Co-hosts, Sixth NBC, at Firodia Auditorium, DES Law College, Fergusson College, Pune, MH, India;

**Sunita VS Bandewar:** September 24-25, 2016 - Medical Ethics Workshop at Dr. B. R. Ambedkar Medical College Hospital, Raipur, Chhattisgarh, India[Session Faculty];

**Sunita VS Bandewar:** May 21, 2016- Organised and conducted one day Research ethics training workshop At Research Methodology Workshop hosted jointly by Nabkrushna Choudhuri Centre for Development Studies (NCDS), ICSSR Institute, Bhuwaneshwar, Odisha; and SCSTRIT Bhubaneshwar, Odisha, India;

**Sunita VS Bandewar:** April 18-23 and May 10, 2016 - Organised and conducted six day Research methods and Research ethics in Social Sciences workshop@ Department of Political Sciences and Public Administration, Savitribai Phule Pune University, Pune, MH, India;

Vijayaprasad Gopichandran: June 2016 - Facilitated WHO-TDR workshop on Ethics of Implementation Research in Ghana;

Vijayaprasad Gopichandran: June 2016 - Presented poster in Internal Association of Bioethics 2016 World Congress in Edinburgh;

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### **E.** Publications on bioethics

**Rakhi Ghoshal:** Ghoshal, R. 2017. 'The overseas child: understanding international surrogacy' (book review of Paula Gerber and Katie O'Byrne (eds.) Surrogacy, Law and Human Rights, 2015, Ashgate Publishing Ltd, England), Indian J Med Ethics. 2017Jan-Mar; 2(1) NS: 62-4.

Rakhi Ghoshal: Co-author of the Conference Report of the 6th NBC, published online in IJME on May 10, 2017;

**Sandhya Srinivasan:** Wrote article on a clinical trial testing brain dead bodies to see if they could be revived, which was also the subject of an FMES complaint "Why an Indo-US project to bring the dead back to life is no laughing matter" Scroll.in. May 31, 2016; https://scroll.in/pulse/808634/why-an-indo-us-project-to-bring-the-dead-back-to-life-is-no-laughing-matter.

**Sandhya Srinivasan:** Co-author of editorial in IJME on the same trial. "Response to proposed research to reverse brain-death: more than regulatory failure. Indian J Med Ethics. 2016; 1(3) NS: 134-7. Available from: http://ijme.in/wp-content/uploads/2016/11/2131-5.pdf

**Sandhya Srinivasan:** Was co-petitioner in Supreme Court public interest litigation (dismissed) on unethical trials of cervical cancer screening, calling for compensation for harmed trial participants and regulation of non-drug trials.

**Sandhya Srinivasan:** Co-author of letter in the Journal of Global Oncology responding to a justification of these trials. (Srinivasan S, Loff B, Johari V, Jesani A, N Sarojini. Researchers' first duty is to the participants. Journal of Global Oncology. 2(4): 246-7.

**Sandhya Srinivasan:** Co-authored with Veena Johari and Amar Jesani - a case study on the cervical cancer screening trials for the TRUST Project. (Schroeder D, Cook Lucas J, Fenet S, Hirsch F (eds) (2016) "Ethics Dumping" – Paradigmatic Case Studies, a report for TRUST, available at: http://trust-project.eu/wp-content/uploads/2016/03/TRUST-664771-Paradigmatic-Case-Studies-WP1-Final.pdf

**Sanjay Pai:** Co-authored with Vaz M, Sridhar TS. The ethics of research on stored biological samples: outcomes of a Workshop. Indian J Med Ethics. 2016 Apr-Jun;1(2):118-22.

**Sunita VS Bandewar:** Bandewar SVS, Wambugu F, Richardson E, Lavery JV. The role of community engagement in the adoption of new agricultural biotechnologies by farmers: the case of the Africa harvest tissue-culture banana in Kenya. BMC Biotechnology (2017) 17:28. DOI 10.1186/s12896-017-0347-4

**Sunita VS Bandewar:** Pisal H and Bandewar SVS. Iccha Sanmane Shevatachi (Marathi publication). Saptahik Sakal. Nov 26, 2016.

**Sunita VS Bandewar :** Schopper D, Ravinetto R, Schwartz L, Kamaara E, Bandewar SVS, Selgelid MJ, Ahmad A, Dawson A., Singh J, Jesani A, Upshur R. Research ethics governance in times of Ebola. Public Health Ethics. Published online Nov 1, 2016. doi:10.1093/phe/phw039

**Sunita Simon Kurpad:** Co-authored Guest editorial with A Bhide on Sexual boundaries in the doctor patient relationship: Guidelines for doctors. Indian J Psychiatry, 2017; 59 (1):14-16;

**Sunita Simon Kurpad:** Authored a Chapter on High Risk Sexual behavior In Ethics in book on Mental Health-Substance Use. Ed David Cooper. CRC Press Taylor and Francis Group. May 2017.

**Vijayaprasad Gopichandran:** Co-authored with Gaitonde R. The Chennai floods of 2015 and the health system response. Indian J Med Ethics. 2016 Apr-Jun;1(2) NS: 71-5.

**Vijayaprasad Gopichandran:** co-authored with Mariaselvam S. The Chennai floods of 2015: urgent need for ethical disaster management guidelines. Indian J Med Ethics. 2016 Apr–Jun; 1(2) NS: 91-5.

**Vijayaprasad Gopichandran:** co-authored with Luyckx VA, Biller-Andorno N, Fairchild A, Singh J, Tran N, Saxena A, Launois P, Reis A, Maher D, and Vahedi M. Developing the ethics of implementation research in health. Implement Sci. 2016; 11: 161. Accessed at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5148832/

**Vijayaprasad Gopichandran:** The IAB Congress 2016: Is there justice in the bioethics world? Indian J Med Ethics. 2017 Jan-Mar; 2(1): 43-44.

### F. Any other bioethics related activity

**Barun Mukhopadhyay:** February 2017 - attended a discussion meeting of Kolkata Network for Promotion of Ethics in Medicine;

**Rakhi Ghoshal:** January 13-15, 2017 - Served as Member, Sub-scientific committee, 6th National Bioethics Conference, Pune, Maharashtra, India;

**Rakhi Ghoshal:** January 13-15, 2017 -Served as Member, Core rapporteuring team at the 6th National Bioethics Conference, Pune, Maharashtra, India.

### MEDIA COVERAGE OF IJME (APRIL 2016 - MARCH 2017)

- Menaka Rao. A new bill on public health emergencies allows for dubious restrictions of citizens' liberties. Scroll. in. March 31, 2017: https://scroll.in/pulse/833283/a-new-bill-on-public-health-emergencies-allows-for-dubiousrestrictions-of-citizens-liberties
- Sarojini Nadimpally, Use of pellet guns has caused a public health crisis in Kashmir. The Wire. March 29, 2017: https://thewire.in/119579/pellet-guns-kashmir-public-health/
- Olinda Timms, More focus needed on palliative care. *Deccanherald.com*. March 25, 2017 http://m.deccanherald.com/articles.php?name=http%3A%2F%2Fwww.deccanherald.com%2Fcontent%2F603006%2Fmore-focus-needed-palliative-care.html
- Vikhar Ahmed Sayeed, A tale of exploitation. Frontline.in, http://www.frontline.in/the-nation/a-tale-of-exploitation/article9583441.ece
- Sanjay Nagral. Government's cap on the absurdly high prices of stents is a good first step. *The Wire*. February 18, 2017: https://thewire.in/110178/maharashtras-stents-is-a-good-first-step/
- TNN. Doctors allege illegal organ trade on the rise in major hospitals too. timesofindia.indiatimes.com February 13, 2017: http://timesofindia.indiatimes.com/city/goa/doctors-allege-illegal-organ-trade-on-the-rise-in-majorhospitals-too/articleshow/57115613.cms
- Menaka Rao, How to create a fever outbreak: Lessons from East Delhi, Scroll.in October 3, 2016: http://scroll.in/ pulse/818024/how-to-create-a-fever-outbreak-lessons-from-east-delhi
- Ivan Oransky, Adam Marcus. Why an obscure Indian journal has an impressive and growing international stature Statnews.com. September 9, 2016: https://www.statnews.com/2016/09/09/ijme-journal/
- Priyanka Vora. Back to basics: Indian Psychiatric Society warns doctors against sexual relations with patients. Scroll.in. September 8, 2016: http://scroll.in/pulse/815938/back-to-basics-indian-psychiatric-society-warnsdoctors-against-sexual-relations-with-patients
- George Thomas, C Rammanohar Reddy, Privileging primary care. *Thehindu.com* August 30, 2016:http://www. thehindu.com/opinion/op-ed/privileging-primary-care/article9046759.ece
- Michael Cook, Bioethicist alleges "publication bias" at NEJM, BioEdge.com, August 20, 2016: http://www.bioedge.org/bioethicist-alleges-publication-bias-at-nejm/11965
- Sreemoyee Chatterjee, Guidelines for doctors on sexual boundaries, professional ethics. TNN. August 19, 2016: http://timesofindia.indiatimes.com/city/bengaluru/Guidelines- for-doctors-on-sexual-boundaries-professionalethics/articleshow/53773296.cms. Also see: http://ijme.in/index.php/ijme/article/view/315/1225
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### **AUDITED FINANCIAL REPORT**

### Name of the Trust: FORUM FOR MEDICAL ETHICS SOCIETY

### Registration No. F-17441 dt. 14-05-1995.

We have audited the annexed Balance Sheet of the FORUM FOR MEDICAL ETHICS SOCIETY as on 31st March 2017 and also the annexed Income & Expenditure Account for the Year ended on the date. Our responsibility is to express an opinion on these financial statements based on our audit.

We conducted our audit in accordance with auditing standards generally accepted in India. Those Standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

We further report that :-

- 1. The accounts are maintained regularly and in accordance with the provisions of the Act and the Rules.
- 2. The receipts and disbursements are properly and correctly shown in the accounts.
- 3. The cash balance and vouchers in the custody of the Manager or Treasurer on the date of audit were in agreement with the accounts.
- 4. All books, debts, accounts, vouchers or other documents or records required by us were produced before us.
- 5. The trust does not own any immovable property. The trust has maintained registers in respect of moveable property.
- 6. The Treasurer or any other person required by us to appear before us did so and furnished the necessary information required by us.
- 7. No property or funds of the Society were applied for any object or purpose other than the object or purposes of the Trust.
- 8. There are no amounts which are outstanding for more than one year and no amount is written off.
- 9. No tenders were invited for repairs or construction, as there was no such expenditure in excess of Rs 5000 incurred during the year.
- 10. The moneys of the Society have not been invested contrary to the provisions of Section 35 of the Act.
- 11. The Trust does not hold any immovable property and as such the provisions of Section 36 of the Act do no apply.
- 12. So far as it is ascertainable from books of accounts and according to the information and explanations given to us there were no cases of irregular, illegal or improper expenditure, or failure or omission to recover moneys or other property belonging to the Society or of loss or waste of money or other property belonging to the Trust.
- 13. The budget required to be filed under Rule 16-A is filed.
- 14. The maximum and minimum number of the members of the Trustees is maintained.
- 15. The meetings are held regularly.
- 16. The minute books of the proceedings of the meeting is maintained.
- 17. None of the Trustees has any interest in the investment of the Trust.
- 18. No Trustee is debtor or creditor of the Trust.
- 19. No irregularity has been pointed out by us in our previous report.
- 20. There is no special matter, which we think fit necessary to bring to the notice of the Deputy or Assistant Charity Commissioner.

For SACHIN P. MULGAOKAR & CO. Chartered Accountants Firm Reg No 108945W

Sd/-

SACHIN P. MULGAOKAR (Proprietor) Membership No 40942

Dated: 12th August 2017

MUMBAI

#### THE BOMBAY PUBLIC TRUSTS ACT, 1950

### SCHEDULE VIII [Vide Rule 17 (1)]

Regn.No.:F-17441(Mumbai)

#### Name of the Public Trust: Forum for Medical Ethics Society Balance Sheet as at 31st March 2017

FUNDS & LIABILITIES	Rs.	Rs.	PROPERTY & ASSESTS	Rs.	Rs.
Trusts Funds or Corpus:-			Immovable Properties (at cost)		
Bal. as per last Balance Sheet	136,157.00		Balance as per Last Balance Sheet		-
Addition during the year		136,157.00	Addition during the year		-
			Less: sales during the year		-
			Depreciation upto date		
Other Earmarked Funds			Investments		
(Created under the provision of the			Market Value of Investments in Rs		-
Trust Deed or out of the Income)					
<b>Contingencies Reserve Fund</b> ( As per last Balance Sheet)		45,000.00	Loans (Secured or Unsecured): Good/Doubtful		
			Loan Scholarships		-
			Other Loans		-
Loans (Secured or Unsecured)			Furniture & Fixtures		
From Trustees		-	Balance as per Last Balance Sheet	40,000.00	
From Others		-	Addition during the year	-	
				40,000.00	
			Less: Deletion during the year		
			Less:Depreciation upto date (Refer Schedule A)	39,144.00	856.00
Liabilities					
For Expenses		-			
Income Tax Payable			Advances		
For Rent and other Deposits		-	To Trustees		-
For sundry Credit Balances			To Employees		-
			To Contactors		-
Life Subscription Fees (Refundable)			To Lawyers		-
As per Last Balance Sheet	430,570.00		To Others (Deposit for Office Premises)		50,000.00
Addition during the year (See Note c in Schedule E)	-	430,570.00	To Tax Deducted at Source		113,858.00
			To Prepaid Expenses		
			Income Outstanding		-
	İ		Rent		-
			Interest		-
Income & Expenditure A/c:-			Cash & Bank Balances		
Bal. as per last Balance Sheet	2,602,052.02		a) In Saving Accounts with The Saraswat co-op. Bank Prabhadevi Br	699,213.81	
Add : Excess of Income over Expenses	(69,205.94)	2,532,846.08			
			b) In saving account With Bank Of India	64,667.27	
			c) Fixed deposit in Sarawat Bank	2,200,000.00	
			d) With the Trustee	15,978.00	2,979,859.08
			Income & Expenditure A/c:-		
Total Rs.		3,144,573.08	Total Rs.		3,144,573.08

Notes : Schedule E

For Sachin P. Mulgaokar & Co. Chartered Accountants Firm Reg No 108945W MUMBAI

Sd/-**Auditors** Mumbai Dated : 12th August 2017 As per our report of even date the above Balance Sheet to the best of my belief contains a true account of the Funds & Liabilities and of the Property and assets of the Trusts.

Sd/-**Trustees** Mumbai Dated : 12th August 2017

### THE BOMBAY PUBLIC TRUSTS ACT, 1950

#### SCHEDULE IX [Vide Rule 17 (1)]

Regn.No.:F-17441(Mumbai)

### Name of the Public Trust: Forum for Medical Ethics Society Income & Expenditure Account for the year ending 31st March, 2017

EXPENDITURE	Rs.	Rs.	INCOME	Rs.	Rs.
Expenditure in respect of Properties		-	Rent		-
Rates, Taxes, Cess		-	Interest		
Repairs & Maintenance		-	On Fixed Deposit with Banks	121,655.00	
Salaries		-	On Saving Bank Account	80,979.00	
Insurance					202,634.00
Depreciation					
Establishment Expenses		-	Dividend		-
Remuneration to Trustees			Donations		75,000.00
Remuneration ( In case of Math )					
Legal Expenses					
Audit Fees		17,250.00			
Contribution to Charity Commissioner		-			
Amount written off		-	Income from Other Sources		
Bad Debts		-	Membership Fees	10,500.00	
Loan Scholarship		-	Subscriptions	138,830.00	149,330.00
Irrevocable Rents		-			
Other Items		-			
Miscelleneous Expenses					
Depreciation		511.00	Grant Received		1,300,000.00
Amount Transferred to Reserve or Specific Fund					
Life Subscription Fees (Refundable) A	ccount		Conference Receipts (Sch B)		2,009,461.86
Contingency Fund		-			
Expenditure on Objects of Trust					
Religious		-			
Educational ( Sch C)		2,308,759.25			
Medical Relief		-			
Relief of Poverty					
Other Charitable objects					
Donation		10,000.00			
Conference Expensess ( Sch D)		1,469,111.55			
		-			
Surplus carried to Balance Sheet		(69,205.94)			
Total Rs.		3,736,425.86	Total Rs.		3,736,425.86

For Sachin P. Mulgaokar & Co. Chartered Accountants Firm Reg No 108945W MUMBAI

Sd/-**Auditors** Mumbai Dated : 12th August 2017 Sd/-**Trustees** Mumbai Dated : 12th August 2017

#### FORUM FOR MEDICAL ETHICS SOCIETY

#### Schedules forming part of the Income & Expenditure Account

#### Schedule A

#### Schedule of Fixed Assets

Sr.	Gross Block			Depreciation			Net Block		
No.	Particular	As at 1-4-2016	Additions	Deletion	As at 31-3-2017	As at 1-4-2016	During the Year	As at 31-3-2017	W.D.V. as at 31-3-2017
1	Computer & Printer	35,000	-	-	35,000	34,252	449	34,701	299
2	Furniture & Fixture	5,000	-	-	5,000	4,381	62	4,443	557
	Total	40,000	-	-	40,000	38,633	511	39,144	856

#### Schedule B

#### **Conference Receipts**

Stall Charges	12,500.00 2,009,461.86
Collaborator Contribution	535,000.00
Registeration Fees	221,961.86
Grant	1,240,000.00

#### **Schedule D**

#### **Conference Expenses**

Total	1,469,111.55
Printing & Stationery	235,169.00
Telephone & Internet Charges	9,209.00
Xerox Charges	502.00
Website Expenses	69,000.00
Hospitality & Meeting Expenses	659,976.00
Legal & Professional Fees	70,700.00
Food Expenses	31,263.00
Misc Expenses	8,875.55
Travel & Conveyance	121,017.00
Honorarium	263,400.00

#### Schedule C

#### Expenses incurred on objects of the Trust (Educational)

inast (Laacational)
225,756.00
1,148,470.00
1,030.25
44,673.00
276,000.00
4,357.00
43,190.00
1,600.00
21,456.00
26,202.00
1,400.00
416,730.00
4,050.00
490.00
10,136.00
2,083.00
7,215.00
49,092.00
24,829.00
2,308,759.25

#### Schedule E

#### **Notes Forming Part of Accounts**

	Major Accounting Policy
	Method of Accounting :
(a)	Method of Accounting followed by Trust is presently on Cash Basis
(b)	Fixed Assets are stated at Cost less Depreciation
(c)	Life Subscription fees (Refundable) Rs.430570-, represents amount refundable to Life subscribers if the Society ceases to publish its Journal "Indian Journal of Medical Ethics".

For Sachin P. Mulgaokar & Co. Chartered Accountants Firm Reg No 108945W MUMBAI

Sd/-**Auditors** Mumbai Dated : 12th August 2017 Sd/-**Trustees** Mumbai Dated : 12th August 2017

#### THE BOMBAY PUBLIC TRUST ACT, 1950

#### SCHEDULE IX C (Vide Rule 32)

#### Statement of Income Liable to Contribution for the year ending 31st March 2017

Name of the Public Trust : Forum for Medical Ethics Society Regn. No.: F-17441 (Mumbai)

	Rs.	Rs.
1.Income as shown in the Income and Expenditure Account (Schedule IX)		3,736,425.86
Note: This being an Educational Society, its income is not liable to contribution		3,736,425.86
The Society makes efforts to educate health care professionals on ETHICS. To		
this end we publish a registered journal ,organise meetings, and conferences.		
take lectures on medical ethics		
II. Items not chargeable to Contribution under Section 58 and Rule 32:		
(I) Donation Received from other Public Trusts and Dharamdas	-	
(ii) Grants recd. From Government and Local authorities		-
(iii) Interest on Sinking or Depreciation Fund		
(iv) Amount spend for the purpose of secular education		-
(v) Amount spend for the purpose of medical relief		-
(vi) Amount spend for the purpose of veterinary treatment of animals	-	
(vii) Expenditure incurred from Donations for relief of distress caused	-	
by scarity, drought, flood, fire or other natural calamity		
(viii) Deduction out of income from lands used for agriculture purposes:-		
(a) Land Revenue and Local Fund Cess		
(b) Rent payable to superior landlord		
(c) Cost of production, if land is cultivated by trust		-
(ix) Deduction out of income from lands used for non-agricultural purposes:-		
(a) Assessment, cesses and other govt. or Municipal taxes	-	
(b) Ground rent payable to the superior landlord		-
(c) Insurance premia		
(d) Repairs at 10 percent of gross rent of building		-
(e) Cost of collection at 4 percent of gross rent of building let out	-	
(x) Cost of collection of income or receipts from securities, stocks etc.		
at 1 percent of such income		
(xi) Deduction on account of repairs in respect of buildings not rented &		
yielding no income, at 10 percent of the estimated gross annual rent	-	-
Gross Annual Income chargeab	le to contribution Rs.	

Certified that while claiming deductions admissible under the above Schedule, the Trust has not claimed any amount twice, either wholly or partly, against any of the items mentioned in the Schedule which have the effect of double deduction.

#### **Trust Address:**

O-18, Bhavna Veer Savarkar Marg Prabhadevi Mumbai 400 025

For Sachin P. Mulgaokar & Co. **Chartered Accountants** Firm Reg No 108945W MUMBAI

Sd/-

**Auditors** Mumbai Dated : 12th August 2017 Sd/-Trustees

Mumbai Dated : 12th August 2017

### THANK YOU!

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The Forum for Medical Ethics Society would like to express its deep appreciation of the generous support under their Corporate Social Responsibility policy from

### **Orient BlackSwan Pvt Ltd,**

a publishing house which has sustained the journal through 2015-2017

FMES also received with thanks, funds for the Sixth *IJME* National Bioethics Conference 2017 from the following institutions:

The Indian Council for Medical Research, New Delhi, India;

Cipla Foundation, Mumbai, India

Narotam Sekhsaria Foundation, Mumbai, India.



### The 14<sup>th</sup> World Congress of Bioethics

&

### The 7<sup>th</sup> IJME National Bioethics Conference

First Announcement: Save the dates

THEME

Health for All in an Unequal World: Obligations of Global Bioethics

DATES AND VENUE

Pre-conference satellite meetings: Monday, December 3, 2018 Main Conference: Tuesday-Friday, December 4-7, 2018 The Ashok: 50-B, Diplomatic Enclave, Chanakyapuri, New Delhi 110021, India http://www.theashok.com/

**CO-ORGANISERS** 

### Forum for Medical Ethics Society (<u>www.ijme.in</u>)

&

Sama Resource Group for Women and Health (<u>http://www.samawomenshealth.in</u>/)

Five plenaries will be woven around these sub-themes of the conference: Bringing Rights and Ethics to the Centre in the 'Health for All' discourse; Rethinking Bioethics Boundaries in the Context of Health for All; Challenges for Bioethics in an Unequal World; Implications of Gender and Sexuality in Bioethics; Interrogating the Construct of Marginalisation and Vulnerabilities as Obligations of Bioethics. Presentation of papers, posters workshops, pre-Congress symposia and conferences will be organized around the conference sub-themes, as well as include themes from within the broader discipline of bioethics.

Watch this space http://iab2018.org





