



**ASSOCIATION OF ORGAN PROCUREMENT ORGANIZATIONS**  
Saving and improving lives through organ, eye, and tissue donation

Hearing Testimony of

**Steve Miller**

Chief Executive Officer  
Association for Organ Procurement Organizations

and

**Joseph Ferreira**

President  
Association for Organ Procurement Organizations

Before the

House Subcommittee on Economic and Consumer Policy

“The Urgent Need to Reform the Organ Transplantation System to Secure More Organs for  
Waiting, Ailing, and Dying Patients”

May 4, 2021

Chairman Krishnamoorthi, Ranking Member Cloud, and members of the Subcommittee, thank you for inviting the Association of Organ Procurement Organizations to testify at this hearing. AOPO is the non-profit organization recognized as the national representative of the 57 federally-designated OPOs responsible for facilitating the organ, eye, and tissue donation process. AOPO leads the nation's organ donation community through innovation, advocacy, and education to pursue the day when every donation opportunity results in lives saved.

My name is Joe Ferreira and I am the President of AOPO. I am joined today by Steve Miller, who is AOPO's Chief Executive Officer. I am also President and CEO of Nevada Donor Network, an OPO considered to be a national and world leader since our transformation in 2012. I have devoted more than half of my life to the mission of honoring donors and their courageous families in the procurement and allocation of organs to people for whom these gifts literally means the difference between life and death. Last year, our amazing team at Nevada Donor Network made the gift of life possible throughout the pandemic with more than 500 organs transplanted to hundreds of transplant recipients. I consider it a true blessing, honor and privilege every day to serve our lifesaving and healing mission on behalf of the heroic donors and those who desperately wait. Further, as a first generation American son of parents who immigrated to the US in the 1960s in pursuit of the American Dream, I consider it a true honor to address you, the leaders of our great country. My mother is a former school teacher from Brazil who runs my father's medical practice. My father, who was also born and raised in Brazil, has been a practicing physician in the United States for more than 40 years and at 81 years young is still on the front lines of the pandemic, taking care of his patients in need despite losing several colleagues and friends to the virus.

Like my father and his colleagues, OPO teams have been on the healthcare front-lines for decades ensuring organ donation is possible despite the challenges. OPOs are non-profit organizations that facilitate organ procurement and provide community awareness on the life-saving importance of donation. To understand their role, it's important to have a sense of the larger organ donation and transplantation system in which they operate. I will take a minute today to explain that system to the Subcommittee. I would also note that, attached to our testimony as Exhibit A is an infographic that depicts the many facets of what OPOs do.

The organ donation process begins when a hospital refers a potential donor to a federally-designated OPO. Eligible donors must be in the hospital with an irreversible brain injury and on a ventilator at or near the time of death. The OPO conducts a medical evaluation to determine donation eligibility and will seek to obtain authorization from the next of kin in collaboration with the hospital care team. Many factors influence the outcome of the donation and transplantation process, including donation authorization, transplant surgeon discretion, donor health records, regulatory considerations, and level of hospital support. A potential recipient match is identified through the national transplant waiting list, overseen by the Organ Procurement and Transplantation Network (OPTN), which is managed by the United Network for Organ Sharing (UNOS). Ultimately, the transplant program must agree to accept the organ offered by the OPO. Many organs are declined by transplant programs for a variety of reasons at their discretion and thus are not utilized. However, if accepted, the organ is recovered, preserved and delivered to the transplanting hospital.

OPOs are the intermediary in the donation and transplantation process; their success is highly dependent on timely hospital referrals and transplant program acceptance. Due to the extremely specific criteria to become a donor, less than 1% of deaths in the U.S. result in deceased organ donation.

While precious few circumstances meet the high standards for organ donation, there is good news. Deceased donors set a record for the tenth year in a row in 2020. Notably, 36,548 organs from 12,588 deceased donors were transplanted, resulting in 33,310 transplants. We have attached to our testimony as Exhibit B an infographic that helps contextualize the numbers behind the organ donation process.

While a number of factors – including the increase in donors – are responsible for the many successive years of record numbers of transplants, I can say first hand that OPOs work tirelessly to ensure as many organs are available as possible to save as many lives as possible. Part of our hard work is aimed at increasing the number of individuals across the country who step forward and agree to be registered organ donors. Over the past ten years, organ donation has increased by 58%. As a result of these improvements since 2010, there are now, on average, 110 lifesaving, deceased donor organ transplants per million population, and 128 living and deceased transplants per million. These are world-leading rates of transplantation that have helped shrink the transplant waitlist.<sup>1</sup>

We are proud of what the OPO community has helped accomplish. At the same time, we can – and must – do better. That is why AOPO supports HHS’s efforts to reform metrics used to assess the effectiveness of OPOs. While AOPO has concerns with some of the metrics introduced by the 2020 OPO Rule, it remains firmly committed to using independently verifiable metrics based on sound data to make the organ donation and transplantation system more efficient. Far from lobbying against such reforms, AOPO has advocated on behalf of its member OPOs as part of a committed effort to work collaboratively with policymakers to develop and implement a performance improvement system that will save more lives through the gift of organ donation and transplantation.

AOPO’s recent advocacy efforts are aimed at ensuring those reforms are thoughtful and driven by science. I must say that I was taken aback by the Subcommittee’s demand for documents relating to these advocacy efforts. And I am very concerned.

By demanding advocacy-related documents, the Subcommittee could discourage OPOs from continuing to affiliate or associate with AOPO in its advocacy efforts, and AOPO and its staff, advisors, and members from engaging in a candid exchange of ideas in planning and preparing for advocacy campaigns. The Supreme Court has long recognized the importance of advocacy groups in our democratic process, and has made clear that the First Amendment shields their speech and associations from government interference. *See NAACP v. Alabama*, 357 U.S.

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<sup>1</sup> See IRODat, *International Registry in Organ Donation and Transplantation* (2021), attached hereto as Exhibit C. Please also note that these increases in deceased organ donation are not attributable solely to the drug overdose epidemic. See D. Stewart, A. Zehner, D. Klassen and J. Rosendale, *The Drug Overdose Epidemic does not Explain all of the Rise in Deceased Donation*, J. of Clinical and Translational Research (2020), attached hereto as Exhibit D.

449, 460 (1958). The law also is clear that “[c]ompelled disclosures concerning protected First Amendment political associations have a profound chilling effect on the exercise of political rights.” *Perry v. Schwarzenegger*, 591 F.3d 1147, 1156 (9th Cir. 2009).

We do not believe that the Subcommittee intends to chill protected advocacy activities, but some of what we have read suggests that the Subcommittee wants to determine our intent in advocating on behalf of our members to improve the OPO Rule. We sincerely hope that today’s hearing will help make it clear that the Committee on Oversight and Reform – with its long history of protecting civil rights – is not seeking to compel the production of protected First Amendment speech.

Thank you, and we look forward to your questions.

# Exhibit A

# HOW THE ORGAN DONATION PROCESS WORKS

Less than **1%**  
**OF DEATHS**  
in the US each year  
result in deceased  
organ donation

**33,309**  
Life-saving organ  
transplants from  
deceased donors  
in 2020

**36,548**  
**ORGANS**  
**TRANSPLANTED**



**~2,800,000**  
US DEATHS

**~715,000**  
ORGAN DONOR MUST  
DIE IN A HOSPITAL

**~150,000**  
ORGAN DONOR MUST  
BE ON A VENTILATOR

**~15-17,000**  
FAMILY AUTHORIZATION  
AND MEDICAL EVALUATION

**12,588**  
DECEASED ORGAN  
DONORS

**42,987**  
RECOVERED ORGANS

MANY FACTORS  
MAY LIMIT THE  
POTENTIAL FOR  
DONATION

RECOVER AND  
TRANSPORT TO  
TRANSPLANT HOSPITAL

ACCEPTANCE BY  
TRANSPLANT PROGRAM

SEARCH FOR A  
DONOR MATCH

regulatory issues - authorization  
hospital records - hospital support  
surgeon preferences - eligibility



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Register your donation decision @ [registerme.org](https://registerme.org) | [aopo.org](https://aopo.org)

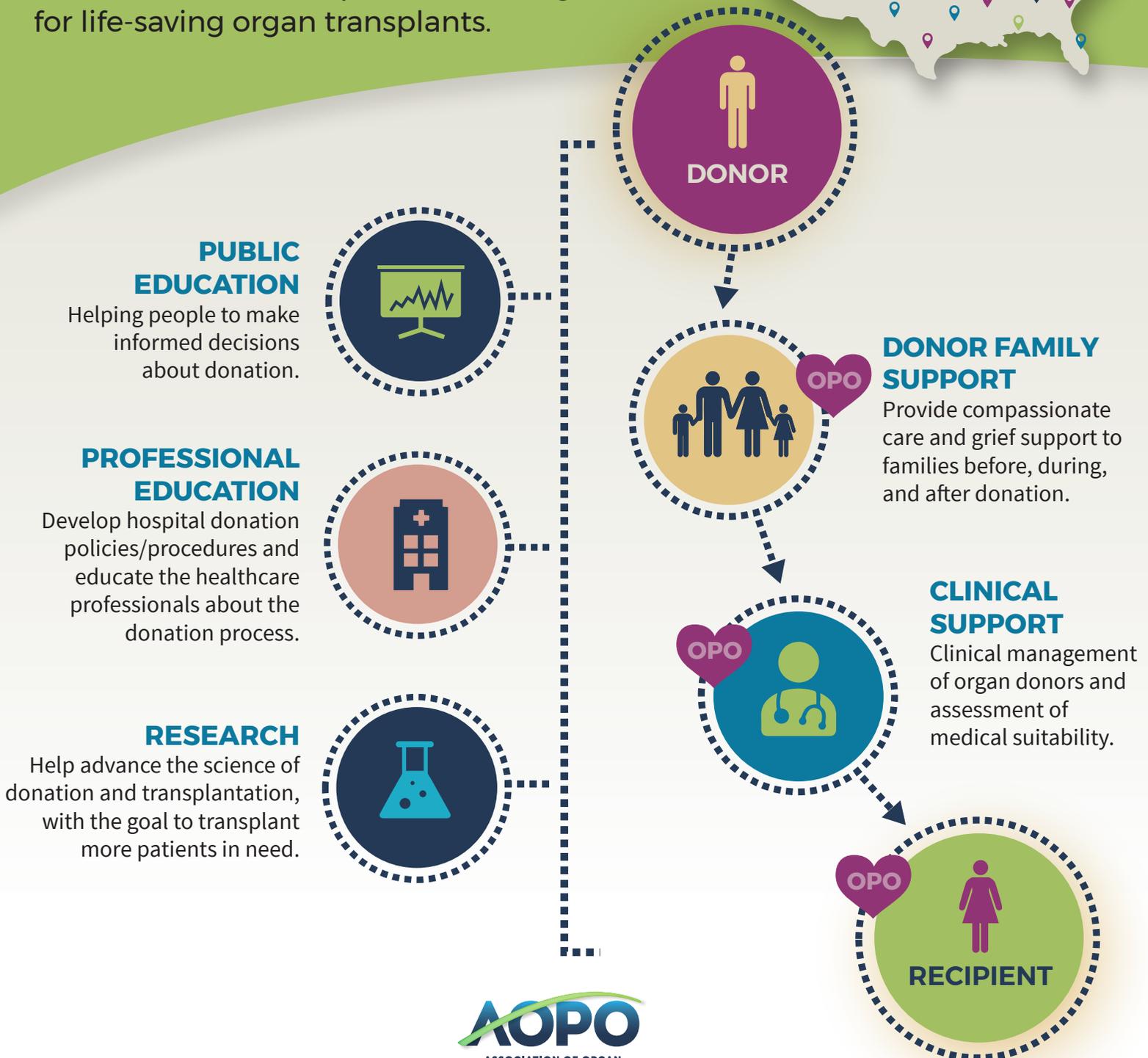
Based on OPTN 2020 Data as of February 10, 2021. Data subject to change based on future data submission or correction.

# Exhibit B

# THE CARING WORK OF ORGAN PROCUREMENT ORGANIZATIONS

## ORGAN PROCUREMENT ORGANIZATIONS (OPOs)

serve as a compassionate and vital link between donors and patients waiting for life-saving organ transplants.



### PUBLIC EDUCATION

Helping people to make informed decisions about donation.

### PROFESSIONAL EDUCATION

Develop hospital donation policies/procedures and educate the healthcare professionals about the donation process.

### RESEARCH

Help advance the science of donation and transplantation, with the goal to transplant more patients in need.

### DONOR FAMILY SUPPORT

Provide compassionate care and grief support to families before, during, and after donation.

### CLINICAL SUPPORT

Clinical management of organ donors and assessment of medical suitability.



# Exhibit C

# IRODaT

## International Registry in Organ Donation and Transplantation

[www.irodat.org](http://www.irodat.org)

Preliminary numbers 2020

February 2021

Dear colleagues

On behalf of the **IRODaT** staff, we are glad to present the 2020 preliminary numbers in organ donation and transplantation.

The mission of **IRODaT** is to support the healthcare professionals, transplant specialist, researchers and general community to have access to verified and validated information.

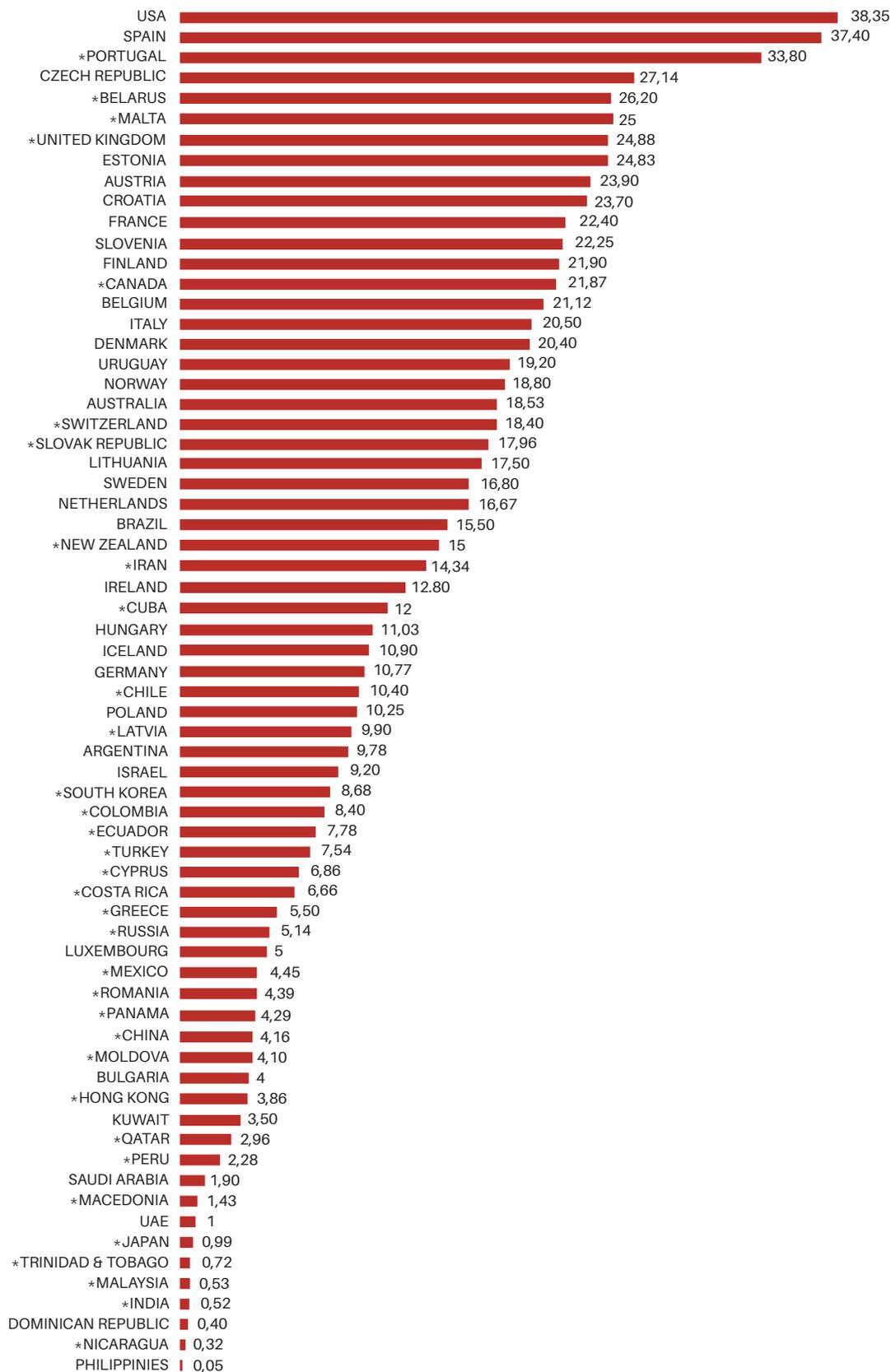
We invite you to visit **IRODaT** website [www.irodat.org](http://www.irodat.org), where you will find information from other countries and news regarding international organ donation and transplantation.

Once again, we would like to thank all your effort in developing the **IRODaT** network around the world and encourage the donation and transplantation activity in your own countries.

**IRODaT Team**



## WORLDWIDE ACTUAL DECEASED ORGAN DONORS RATE 2020 (pmp)

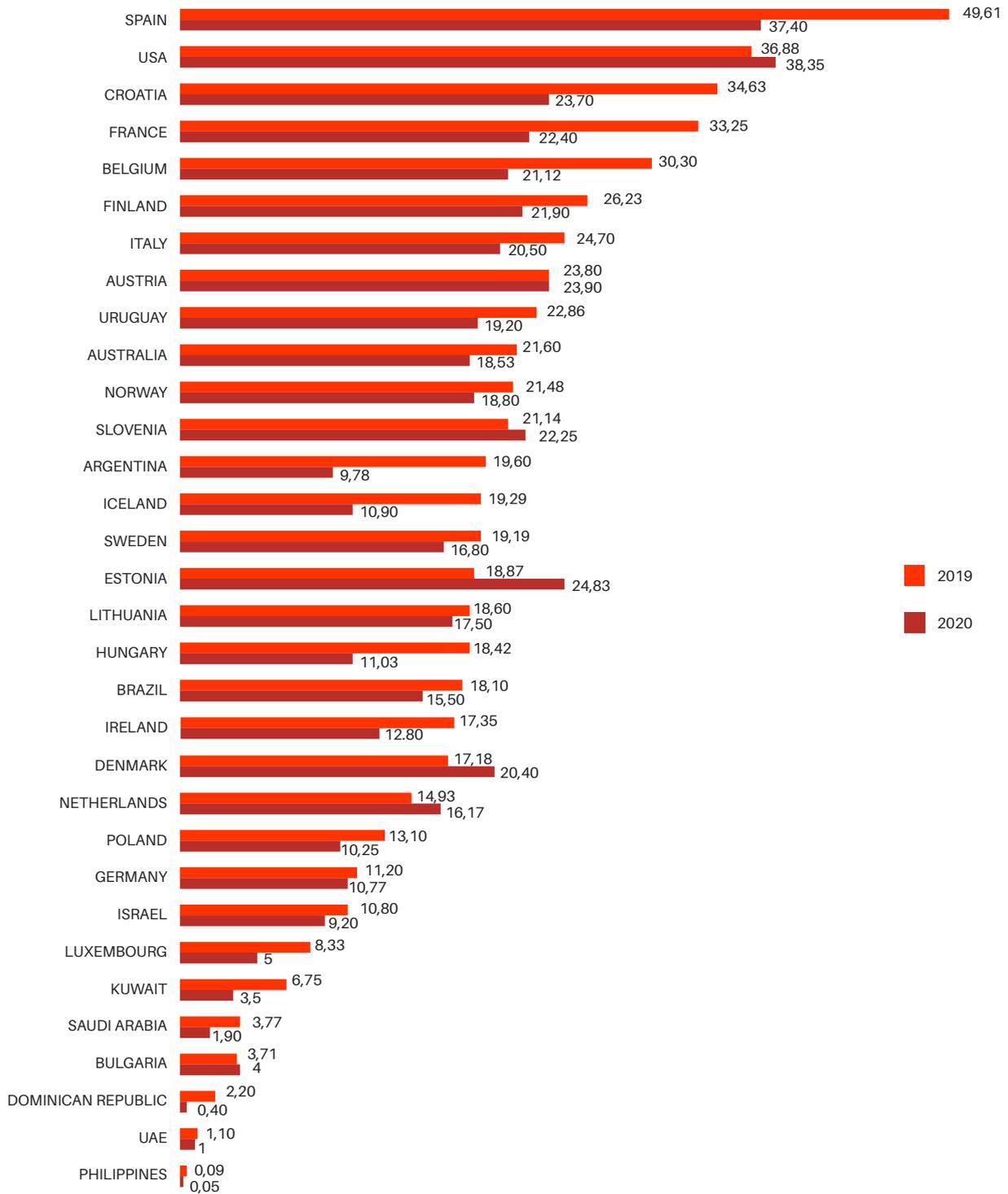


\*Data from 2019

Total Utilized Donors : France, Finland, Canada, Belgium, Italy, Denmark, Norway, Australia, Sweden, Netherlands, Brazil, Hungary, Iceland, Germany, Luxembourg

Brazil : data from Jan to Sep 2020

**WORLDWIDE ACTUAL DECEASED ORGAN DONORS RATE 2019 vs 2020 (pmp)**



Total Utilized Donors: France, Belgium, Finland, Italy, Australia, Norway, Iceland, Hungary, Brazil, Denmark, Netherlands, Germany, Luxembourg  
 Brazil : data from Jan to Sep 2020

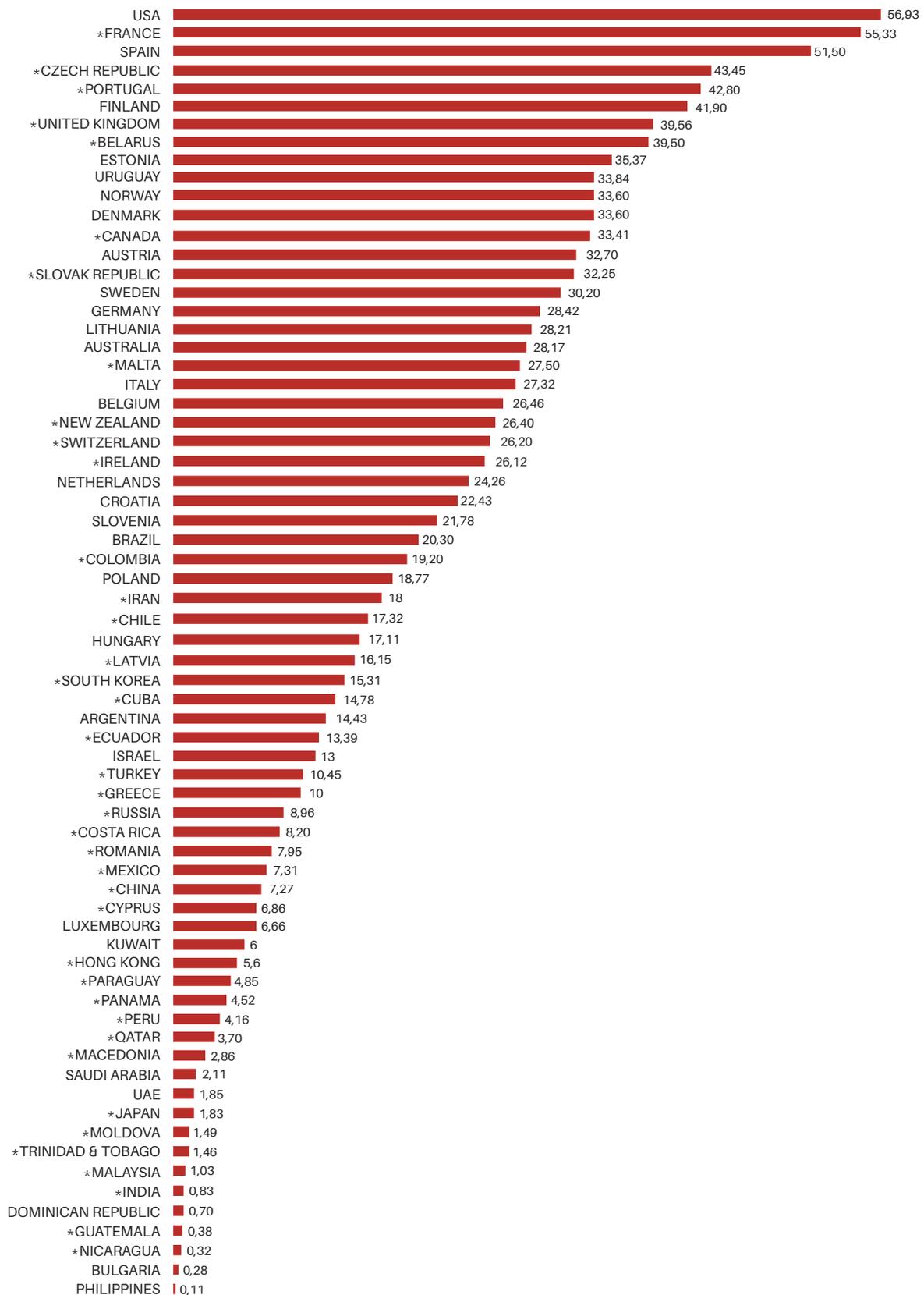
# TRANSPLANTATION ACTIVITY

**IRODaT** presents in this section the transplantation worldwide activity of 2020. It is divided into seven figures, each represents a different organ transplant activity (kidney, liver, heart, lung and pancreas).

All graphs are represented in pmp, and the figures regarding transplant from deceased donors' numbers had included all combinations.

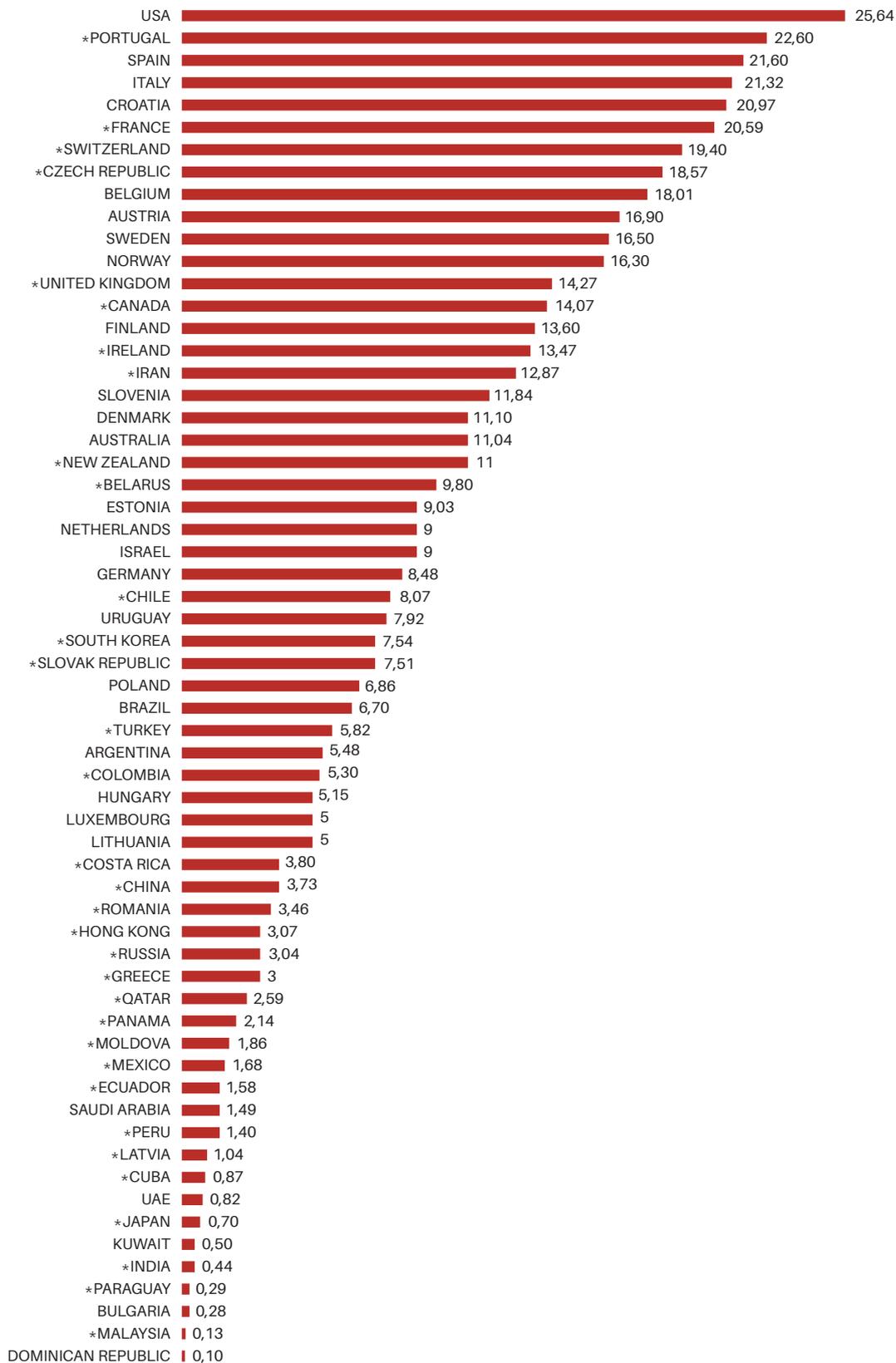
Remind that all this information and figures, as well as this Newsletter are available in **IRODaT** website [www.irodat.org](http://www.irodat.org)

## WORLDWIDE KIDNEY TRANSPLANT FROM DECEASED DONORS RATE 2020 (pmp)



\* Data from 2019

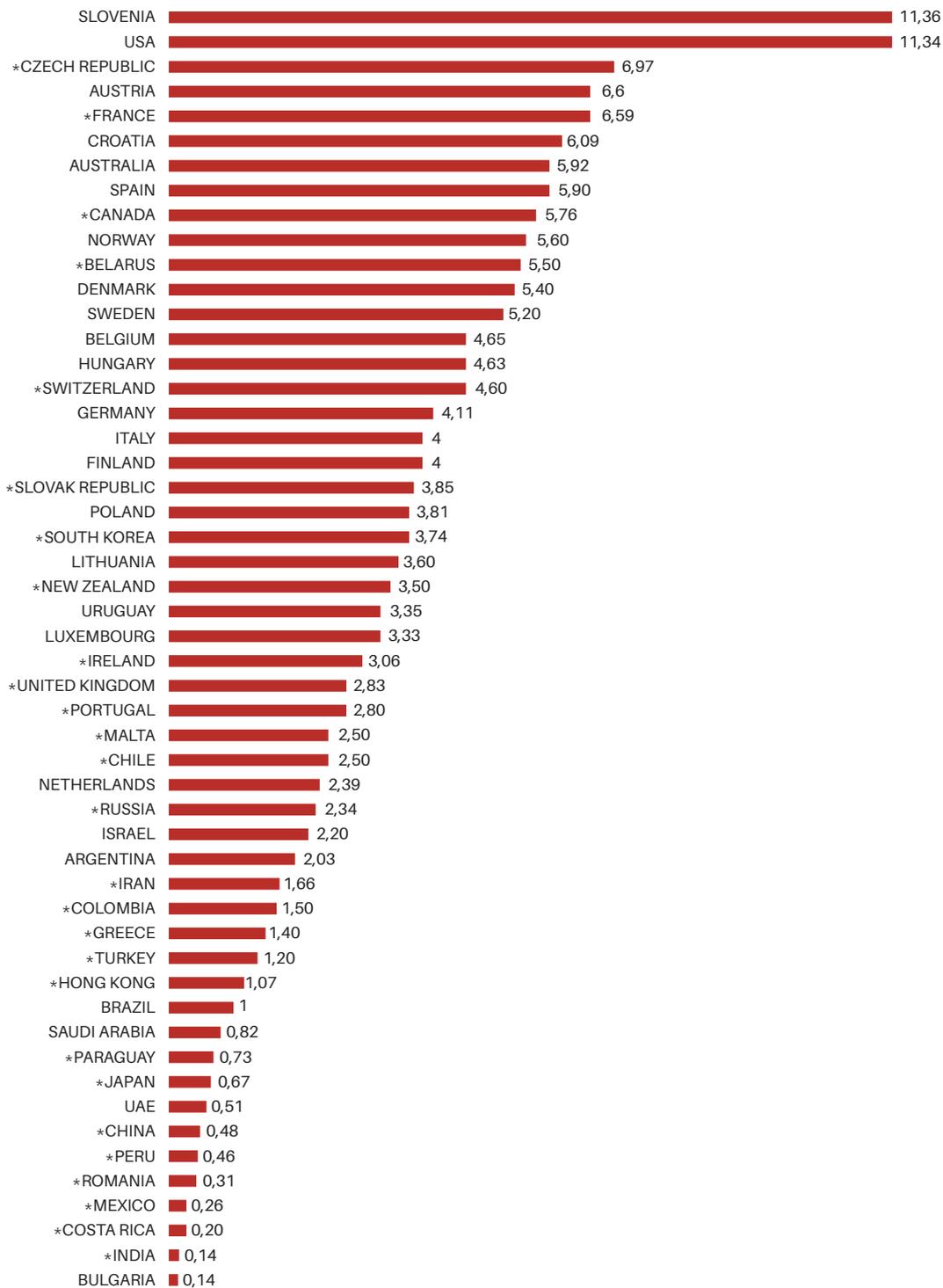
## WORLDWIDE LIVER TRANSPLANT FROM DECEASED DONORS RATE 2020 (pmp)



\*Data from 2019

Brazil : data from Jan to Sep 2020

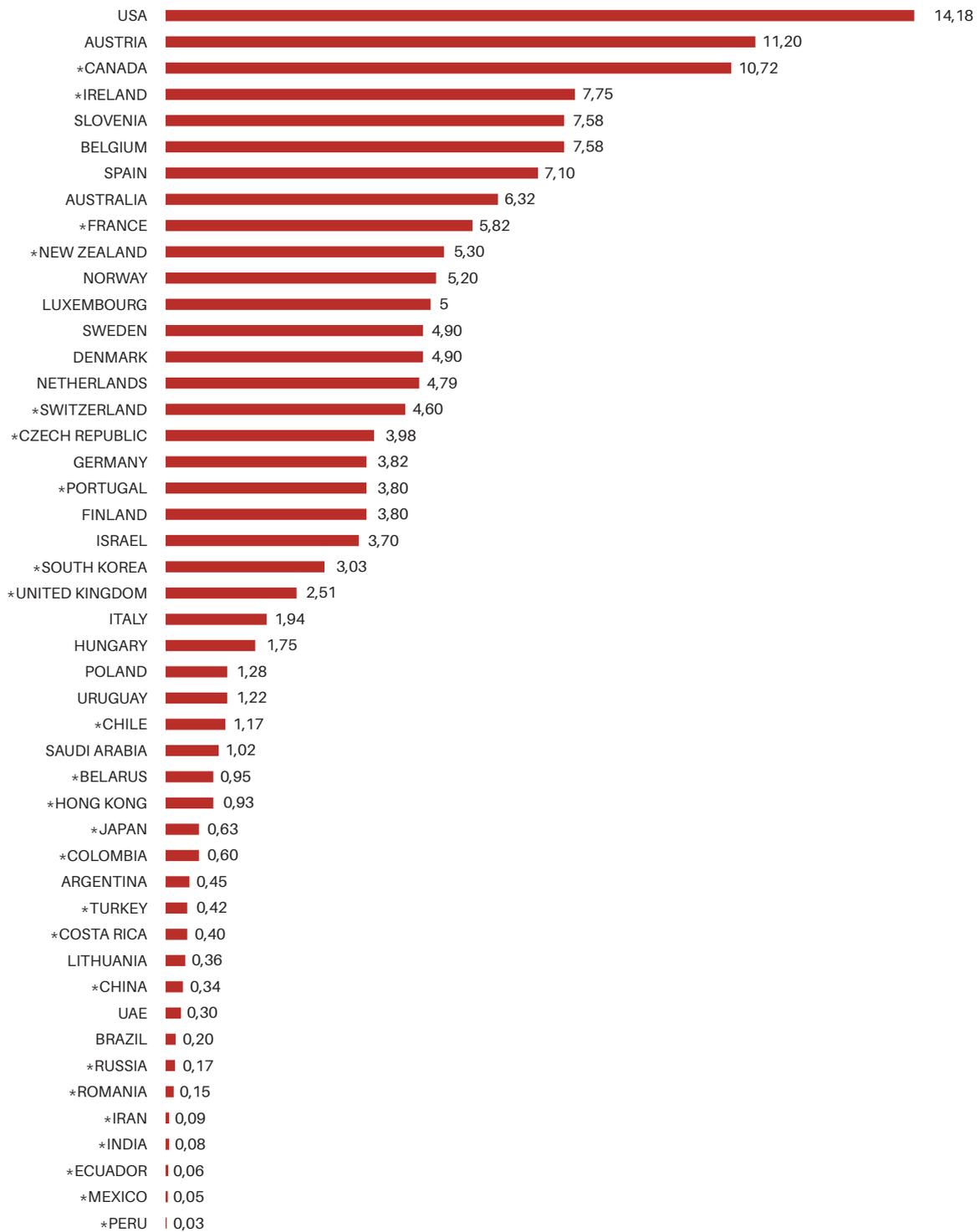
## WORLDWIDE HEART TRANSPLANT RATE 2020 (pmp)



\*Data from 2019

Brazil : data from Jan to Sep 2020

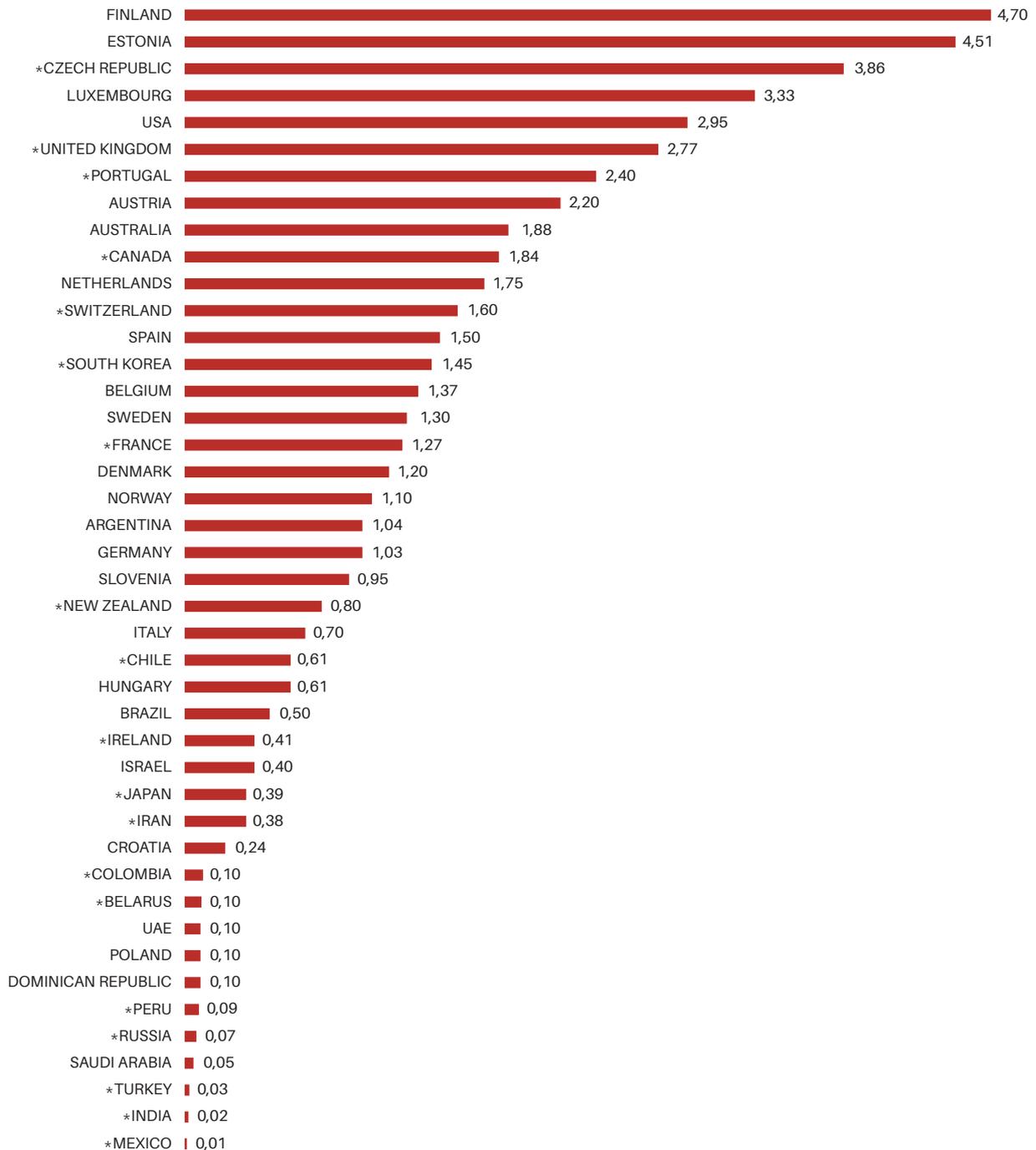
## WORLDWIDE LUNG TRANSPLANT RATE 2020 (pmp)



\*Data from 2019

Brazil : data from Jan to Sep 2020

## WORLDWIDE PANCREAS TRANSPLANT RATE 2020 (pmp)



\*Data from 2019

Brazil : data from Jan to Sep 2020

# OFFICIAL REPORTERS

Thanks to the Official Reporters it was possible to make this publication. The list of the reporters is available on **IRODaT** website [www.irodat.org](http://www.irodat.org)

## DISCLAIMER OF INFORMATION VARIATION

International Registry in Organ Donation and Transplantation, **IRODaT** is not responsible of any modification that the Official Reporters may do on their own country data after this Newsletter publication. The Official Reporters are the final responsible of the information.

# Exhibit D



## LETTER TO THE EDITOR

# The drug overdose epidemic does not explain all of the rise in deceased donation

In their brief communication<sup>1</sup>, Goldberg and Lynch attempted to answer a vital question: is the 37% rise in deceased organ donation over the past decade solely attributable to the drug overdose epidemic?

After close inspection, we find the authors' conclusion "it is indisputable that nationally the increased number of donors is almost wholly attributable to the drug epidemic" to be unsupported by the data.

The authors anchored their analysis on a logical fallacy—that "drug-related" deaths are deaths in which the decedent had any history of drug abuse. This rationale is akin to designating car crashes involving drivers who ever drank alcohol as "DUI-related" accidents.

Of the 24 888 donors classified in Table 1<sup>1</sup> as "Other mechanism of death; non-intravenous drug use," the OPTN database indicates that 9559 (38%) were reported as *not* having continued drug use within the past 6 months, based on an available data field apparently not considered by the authors. Furthermore, 4337 (17%) were reported as having head trauma as cause, "blunt injury" as mechanism, and motor vehicle accident as circumstance of death, making the classification of such deaths as overdose-related purely speculative. (OPTN data)

The authors suggest that 102% of the rise in donation is attributable to the drug epidemic. Our calculations suggest that while the drug epidemic has certainly made an impact on donation, it is not the sole reason for the increase. Adapting to the epidemic by recovering >1000 more drug intoxication donors in 2018 vs 2009 itself reflects OPO and system-wide process improvement; the fact that the entire rise in donation cannot be linked to drug abuse opens the possibility that there have been meaningful improvements in other areas as well.

The number of donation after circulatory death (DCD) donors rose 132% from 2009 to 2018, a trend closely linked to OPO performance improvement<sup>2</sup>. In 2018, just 12% of DCDs had drug intoxication as mechanism of death (OPTN data). Among non-DCDs, the number of organs transplanted per donor rose from 3.17 in 2009 to 3.34 in 2018<sup>3</sup>.

Unjustifiably concluding that the donor increase is "merely the by-product of circumstance"<sup>4</sup> may disincentivize efforts to identify and disseminate best practices that can boost system improvement. Further system improvement through spreading effective practices, policy changes, and developing better performance metrics is imperative.

## ACKNOWLEDGEMENTS

This study used data from the Organ Procurement and Transplantation Network (OPTN). The OPTN data system includes data on all

donors, wait-listed candidates, and transplant recipients in the United States, submitted by the members of the Organ Procurement and Transplantation Network (OPTN), and has been described elsewhere. The Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services provides oversight to the activities of the OPTN contractor.

The data reported here have been supplied by the United Network for Organ Sharing (UNOS) as the contractor for the Organ Procurement and Transplantation Network (OPTN). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy of or interpretation by the OPTN or the US Government.

## CONFLICT OF INTEREST

None.

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