

## RUBBISH HAUL FOUND IN STOMACH OF DEAD WHALE IN TAIWAN

**TAIPEI:** Taiwanese marine biologists have discovered a mass of plastic bags and fishing net in the stomach of a dead whale, underlying the dangers posed by floating ocean trash. The 15-metre (49-foot) mature sperm whale was spotted stranded off the southern town of Tongshih on October 15. Coastguards and scientists returned it to the ocean but three days later it was found dead around 20 kilometers (12 miles) away. Marine biologists from a local university who conducted an autopsy over the weekend found a mass of plastic bags and fishing net sizeable enough to fill an excavator bucket.

Professor Wang Chien-ping, head of the

whale research centre at National Cheng-Kung University, said the garbage was probably a major factor in the death. Wang told AFP the whale could have suffered heart or lung disease and multiple infections. "But... the large amount of man-made garbage in the stomach could reduce its appetite and cause malnutrition. It was likely a critical cause of death." The Society of Wilderness said the case highlighted the growing threat from ocean trash. "We frequently heard of marine animals killed after swallowing lots of garbage, but this one was the biggest in size for many years," said He Chih-ying, spokeswoman for the conservation group. —AFP



**TAINAN, Taiwan:** This handout photo taken on October 24, 2015 and released by the Marine Biology and Cetacean Research Center of National Cheng-Kung University yesterday shows a group of marine biologists conducting an autopsy on a dead sperm whale in the southern Taiwanese city of Tainan. —AFP

## MERS, EBOLA, BIRD FLU: SCIENCE'S BIG MISSED OPPORTUNITIES

**LONDON:** Anyone who goes down with flu in Europe this winter could be asked to enrol in a randomised clinical trial in which they will either be given a drug, which may or may not work, or standard advice to take bedrest and paracetamol. Those who agree could be helping the world prepare for the next potentially deadly disease pandemic as well as helping scientists who are now desperate to plug gaps in knowledge left by previous missed opportunities. Scientists are largely in the dark about how to stop or treat the slew of never-seen-before global health problems of recent years, from the emergence of the deadly MERS virus in Saudi Arabia, to a new killer strain of bird flu in China and an unprecedented Ebola outbreak in West Africa.

They have been unable even to pin down where they came from. That is because vital studies to analyze transmission routes and test experimental drugs or vaccines have simply not been done during epidemics, disease experts say. It is a failure of science, they say, that should not be allowed to happen again.

"Research in all of the epidemics we have faced over the past decade has been woeful," said Jeremy Farrar, director of the Wellcome Trust global health foundation and an expert on infectious diseases. "The world is at risk because there are huge gaps in our knowledge base. We don't now have a vaccine for SARS if it came back tomorrow; we don't know how to treat MERS; it took us six to nine months before we started clinical trials of vaccines for Ebola and in the meantime almost 12,000 people lost their lives; and during the H1N1 pandemic, the number of people randomized into clinical studies was very close to zero."

### 'Byzantine process'

Bureaucracy, logistics and lack of forethought are the heart of the problem, according to Trudie Lang, professor of Global Health Research at Oxford University who has been working on ways to lower such barriers. During the Ebola outbreak that swept through Guinea, Liberia and Sierra Leone, Lang's team, which specializes in planning and operating trials in vulnerable populations in difficult settings, was tasked with setting up a clinical study of a potential Ebola treatment called brincidofovir. "It normally takes 18 months to set up a trial, and we did it in 16 weeks," she told Reuters. "But the problem was we were still behind the curve."

In the 2009 H1N1 "swine flu" pandemic, when many governments had stockpiled antiviral drugs such as Roche's Tamiflu and GlaxoSmithKline's Relenza and doctors prescribed them, often as a preventative measure without a confirmed diagnosis, no proper randomized clinical trials were conducted to find out for sure whether they helped. This has left health officials with little or no concrete evidence on which to base treatment decisions when the next pandemic flu strain threatens the world.

"It is a huge pity we haven't made the most of our opportunity to generate evidence," said Chris Butler, a clinical professor at Cardiff University's Institute of Primary Care & Public Health, who is now working on the European-wide winter flu trial he hopes will help plug the evidence gap. There is little doubt that launching clinical trials in an outbreak is fraught with difficulty, partly because a new or rare strain of disease can infect so many and overwhelm health services

and partly because there are many bureaucratic hurdles.

Lang's team were awarded funds in September 2014 and by January 2015 were able to start the trial, but this coincided with a sharp drop in the number of patients with Ebola as the West Africa outbreak was beginning to plateau. Scientists point to vast amounts of form filling, box ticking, contract drafting, committee meeting and agreement signing that are involved in setting up a clinical trial.

"There's a huge industry around making trialists 'walk through treacle'," said Butler. "There's a myriad of permissions needed. It's a Byzantine process... which can take months. It gives me a headache just thinking about all the approvals" from ethics committees, sponsors, lawyers, research and development leaders and clinicians, he said. Legal agreements are needed between the suppliers of the product—the experimental drug, vaccine or other intervention—and the people running the trial, the funder and hospitals, clinics or health centers where patients will be recruited.

In an infectious disease outbreak scenario, particularly a fast-moving one like with flu or Ebola, these legal issues can be compounded by competition for access to patients. During the Ebola epidemic for example, Lang says, there were five or six different research groups seeking to set up and run clinical trials in the three most affected countries, each of which already had limited health systems that had been overwhelmed and crushed by the outbreak. "It was ludicrous," she told Reuters. "Because essentially we all had to fight over the same patients. It was like a land grab, and by that time the (new) cases were going down."

### Thinking ahead

Part of the threat of any disease outbreak, be it Ebola in Africa, the 2003 outbreak of Severe Acute Respiratory Syndrome (SARS) epidemic, Middle East Respiratory Syndrome (MERS) in Saudi Arabia or the new H7N9 bird flu in China, is the unknown. Yet Lang and others say there is nothing to say the sorts of clinical trials needed in an epidemic cannot largely be drawn up, agreed, signed and sealed ahead of time.

"We need to have protocols ready to go, we need to have a task force of research staff in each region on standby to be deployed into the next outbreak trials," she said. Legal contracts, for instance, cover broadly the same things for any trial—data sharing and storage, patient confidentiality, informed consent, the timing and publication of results, and the pricing, production and availability of the product if and when it proves useful.

And in a rapidly moving outbreak which may be too swift and deadly to allow for months of organization, a coordinated approach would overcome the problem of having multiple research groups with not enough patients.

This would be both scientifically and ethically preferable, said Lang, since if a trial has to be stopped because it runs out of participants with the relevant disease, then everyone who has taken part until then has run a needless risk.

"The main issue is that this needs to be done in days rather than weeks or months," she said. "That basically means research has to be embedded in the immediate response to an outbreak, and not come as an afterthought." — Reuters

## PATIENTS, DONORS IN 3-HOSPITAL KIDNEY SWAP MEET IN DETROIT

**DETROIT:** It was a donation chain linking three patients from three Michigan hospitals to three strangers willing to give them working kidneys. The surgery involved three people who wanted to give kidneys to loved ones but weren't matches for them. Instead, each was compatible to other patients through a pair kidney donation program. The donors were a husband who wanted to give a kidney to his wife at Beaumont Hospital in Royal Oak; a friend who wanted to help her buddy at the University of Michigan Medical Center in Ann Arbor; and a daughter who wanted to help save her mother's life at Henry Ford Hospital in Detroit.

The donors and patients met for the first time Thursday at Henry Ford Health System in Detroit. The meeting came three months after successful transplants July 22. Kim Yarbrough, 52,

of Detroit, praised her adult daughter, Markesia Valentine, who donated her kidney as part of the program. "Without her, I couldn't even begin to get in the program," Yarbrough said. "And the individual who gave me the kidney is also my hero. And I just really, really feel so blessed." Valentine's kidney went to a woman at Beaumont Hospital, north of Detroit. Yarbrough received a kidney from a donor at the University of Michigan Medical Center.

A donor kidney from Beaumont was sent to Ann Arbor for a patient at the University of Michigan. "Paired kidney donation can shave months off the wait list for patients," said Dr Lauren Malinzak, transplant surgeon and paired donation program director at Henry Ford. "And with the crucial need for donor kidneys, it can provide life-saving options." — AP

## EATING SAUSAGES, HAM, 'PROBABLY' RED MEAT CAUSES CANCER

**PARIS:** Eating sausages, ham and other processed meats causes colon cancer, and red meat "probably" does too, a UN agency said yesterday in a potentially heavy blow for the global meat industry. The analysis of 800 studies from around the world by the International Agency for Research on Cancer (IARC) found "sufficient evidence in humans that the consumption of processed meat causes colorectal cancer." The category includes meat that has been salted, cured, fermented or smoked hot dogs, sausages, corned beef, dried meat like beef jerky or South African biltong, canned meat or meat-based sauces. The finding supports "recommendations to limit intake of meat"—particularly in processed forms, said the IARC.

"In view of the large number of people who consume processed meat, the global impact on cancer incidence is of public health importance," IARC official Kurt Straif said in a statement. For an individual, the risk of getting cancer from eating processed meat was statistically "small," the agency said, but "increases with the amount of meat consumed." "Each 50-gramme (1.8-ounce) portion of processed meat eaten daily increases the risk of colorectal cancer by 18 percent," it said in a statement. For unprocessed red meat—beef, veal, pork, lamb, mutton, horse or goat, the review found "strong" evidence of a cancer-causing effect, but not sufficient to place it in the same group of cancer-causing agents as tobacco smoke, asbestos, and now also processed meat. As for processed meat, the red meat risk was mainly for cancer of the colon and rectum, but also the pancreas and prostate, said the report. The agency cited research attributing about 34,000 cancer deaths per year worldwide to diets high in processed meat.

As for red meat—if the suspected link were to be confirmed—it would account for some 50,000 cancer deaths per year worldwide. The numbers were dwarfed by the estimated one million cancer deaths per year due to tobacco smoking,



**MCLEAN, Virginia:** In this Jan 18, 2010 file photo, steaks and other beef products are displayed for sale at a grocery store. — AP

600,000 from alcohol use, and more than 200,000 due to air pollution, said the agency.

### 'Tortured data'

Meat producers slammed the report, as independent experts urged caution in interpreting the numbers. The North American Meat Institute (NAMI) said the IARC "tortured the data to ensure a specific outcome." "Followers of the Mediterranean diet eat double the recommended amount of processed meats. People in countries where the Mediterranean diet is followed, like Spain, Italy and France, have some of the longest lifespans in the world and excellent health," said Betsy Booren, NAMI vice president of scientific affairs. British nutrition expert Elisabeth Lund said via the Science Media Centre: "Very few people in Europe

eat sufficient meat to fall into the high meat consumption category." "Meat is such a good source of iron and zinc and many women are short of these key micronutrients... Iron is much more... available from meat than from vegetables or supplements." According to Ian Johnson, a Britain-based nutrition researcher, "there is little or no evidence that vegetarians in the UK have a lower risk of bowel cancer than meat-eaters." The report of the IARC, based in Lyon, France, was compiled by 22 experts from 10 countries. Given that red meat is an important source of human nutrition, the results should help governments and regulatory agencies balance the risks and benefits of eating meat, it said. The agency made no finding on whether the method of cooking meat affects cancer risk. — AFP

## FAMILY STUNTS DISABLED DAUGHTER'S GROWTH TO EXPAND HER WORLD

**BALI, Indonesia:** Charley Hooper is so disabled that her mother considers her "unable." At 10, she cannot speak, walk or see anything beyond light and dark and perhaps the shadowy shape of a face held inches away. As she grew bigger, her parents feared she would eventually become too heavy to take anywhere. So Jenn and Mark Hooper came up with a radical solution. The New Zealand couple gave their daughter hormones to stop her growth. Then they had doctors remove her womb to spare her the pain of menstruation. Charley is now around 1.3 meters tall (4 foot 3) and 24 kilograms (53 pounds), and will remain so for the rest of her life. A small but increasing number of families across the US, Europe and New Zealand are turning to what is known as growth attenuation in an attempt to improve the lives of their disabled children.

The practice is highly controversial: Many see the very idea of stunting and sterilizing the disabled as a violation of human rights. But parents such as the Hoopers say it helps their children preserve their quality of life. "We haven't stopped her doing anything. Growing would have stopped her doing things," Jenn says. "We didn't take away any choices that weren't already taken from her." Back in the 1950s and 60s, growth attenuation - which refers only to the hormone treatment - was sometimes prescribed for girls who were expected to grow very tall. But the first known case of stunting a disabled child to ostensibly improve her life popped up in a medical journal in 2006. A Seattle couple wanted to keep their daughter, Ashley, small enough to participate in family activities as she grew up. So doctors gave her high doses of hormones that pushed her body into early puberty and stunted her growth, and removed her uterus and breast buds to prevent discomfort.

### Not widely accepted

More and more doctors have since received requests for growth attenuation. In a recent survey of the Pediatric Endocrine Society, most of whose members are in the US, 32 of 284 respondents said they had prescribed growth-stunting hormones to at least one disabled child. But the practice is by no means widely accepted. Many doctors consider the treatment invasive and unnecessary, and refuse to prescribe it. The public, too, often reacts with everything from unease to revulsion. "People are really entitled to grow and to become the people they



**BALI, Indonesia:** Jenn, left, and Mark Hooper sit for a photo with their three children, from left, Cody, Zak and Charley. — AP photos

were meant to be," says Margaret Nygren, CEO of the American Association on Intellectual and Developmental Disabilities. "Would you ever want this kind of treatment done to you without your consent or knowledge? And if the answer is no, then why would one want to do that to someone else?"

Yet for Charley's parents, that question is moot, because they have never been able to ask for her consent on anything. They have always had to imagine what their daughter would want. Charley is a jumble of uncontrolled limbs with a floppy head that needs supporting. Her parents try to interpret what she feels by the pitch and volume of her moans, and whether her freckled face is relaxed or contorted in a gaping yawn because of intense muscle contractions. The warm sun on her skin can trigger a smile, but is it a sign of joy or a reflex?

### Relax muscles

After reading about Ashley, they convinced Paul Hofman, a pediatric endocrinologist in Auckland, New Zealand, that stunting Charley would help her.

But the local ethics board dismissed the treatment as unnecessary. So Jenn proposed a compromise: If she started the treatment outside New Zealand, could local doctors continue it at home? The board said yes. The family found a doctor in South Korea who gave them the hormones. Within days, they say, her seizures stopped and her stiff limbs became more pliable. Hofman says that may be because estrogen changes neurological activity and can relax muscles.

At 6, she began bleeding now and then in the way women sometimes do on birth control pills. Worried that she would have severe period pain like Jenn, the Hoopers discussed a hysterectomy. She would never be able to consent to sex, they reasoned, let alone to pregnancy. The ethics board approved it. Charley was 7 when doctors removed her uterus. It took nearly four years before she stopped growing. Today, Charley joins her family on trips to the mall and vacations to Bali. Her parents soothe her by cuddling her in their laps and carrying her in their arms. — AP