

MARCH ISSUE 2019

We are CME L! Welcome to the twenty-fifth issue of the CME L Newsletter! This publication aims to update you on the latest news and information in the biomedical world. We will also share information about upcoming events, so stay tuned! Find out more about [CME L](#). We also have a Facebook page, you can follow us [here](#).

## Top stories in this newsletter

### In the News: **Calls for a central registry of human genome editing research and a global moratorium**



In further news about gene editing, a World Health Organization (“WHO”) panel has requested the WHO to establish a central registry on human genome editing research and a group of scientists and ethicists have called for a global moratorium on all clinical uses of human germline editing, that is, changing heritable DNA to make genetically modified human children. Click [here](#) for a news article on the request to establish a registry and [here](#) for a news article on the call for a moratorium.

世界衛生組織(“世衛”)的一個委員會最近要求世衛就所有人類基因組編輯研究設立一個中央註冊制度，[按此](#)閱讀更多。另外，多名科學家和倫理學家呼籲全球暫停所有臨床人類生殖細胞編輯(即透過改變遺傳的去氧核糖核酸(DNA)以製造基因改造人類兒童)，[按此](#)閱讀更多。

### **Hong Kong government launched a trust service for the parents, siblings and relatives of persons with special needs**

The Hong Kong government has launched a Special Needs Trust service. Provided that the other eligibility requirements are met, any parent/ sibling/ relative of a person with intellectual disability, autism or mental disorder may appoint the Director of Social Welfare Incorporated as a trustee to hold money from him/ her (the parent/ sibling/ relative) (“the settlor”) on a Special Needs Trust for the benefit of the person with intellectual disability, autism or mental disorder (“the beneficiary”). When the trustee is notified of the death of the settlor, it will activate the trust account. Then the trustee will regularly disburse trust funds to the carer specified by the settlor for implementation of the care plan prepared for the beneficiary by the settlor. Some are worried that the requirement for the settlor to inject a minimum amount of around HK\$200,000 in order to set up the trust account and the imposition of an annual fee of HK\$21,000, which fee is payable after activation of the trust account, will sideline those with low-income. Read more [here](#).

香港政府推出特殊需要信託服務。若符合申請資格，任何有特殊需要(智障、精神紊亂或自閉症)的人士的父/母/兄/弟/姊/妹親屬(“委託人”)可指定社會福利署署長法團以特殊需要信託受託人的身份為上述有特殊需要的人士(“受益人”)持有來自上述父/母/兄/弟/姊/妹親屬的資金。受託人會在獲通知委託人離世後啟動特殊需要信託戶口，屆時受託人將定期從信託資金發放款項予委託人所指定的照顧者使該照顧者可以此等款項執行委託人生前為受益人準備的照顧計劃。不少人擔心委託人須注入最少大約 200,000 港元才能開立特殊需要信託戶口的規定及啟動戶口後每年 21,000 港元的費用會令低收入者難以得益。[按此](#)閱讀更多。

### **Opt-out organ donation bill passed into law in England**

An opt-out organ donation bill was recently passed into law in England. Adults will be deemed to have consented to be an organ donor and will be considered potential donors when they die unless they chose to opt out or are in one of the excluded groups. Deemed consent will not apply where a person who stood in a qualifying relationship to the deceased adult (his/her partner, specified family member or friend of long standing) immediately before death provides information that would lead a reasonable person to conclude that the deceased adult would not have consented. The changes will take effect in 2020. Click [here](#) for a news story on this and [here](#) for the Explanatory Notes to the new law.

最近英格蘭通過預設默許器官捐贈的法案。新法例之下，成人除非生前選擇不參與或屬被排除的人士，否則將被視為同意於死後捐贈器官，而如果與成年死者有指定關係的人(伴侶、指定家庭成員或長期朋友)在緊接死亡前提供會使合理的人得出該成年死者不會同意捐贈器官的結論的資料，該成年死者將不被視為同意於死後捐贈器官。這些變化將於 2020 年生效。請[按此](#)查看相關新聞及[按此](#)閱讀新法例的註釋。

### In Commentary: **Medical machine-learning models might be susceptible to unethical manipulation**



Researchers are concerned that, as the outputs of medical machine-learning systems might be manipulated by making small but carefully designed changes to the inputs, these systems might be vulnerable to manipulation in ethically questionable ways by players in the health care system for ulterior purposes such as maximizing the money coming their way. Such manipulation might harm patients. Click [here](#) for a relevant commentary.

研究人員擔心，由於人們可能得以透過對輸入數據作精心設計的小更改來操縱醫療機器學習系統的輸出，醫療機器學習系統有可能因此被各方以不符合倫理的方式操縱以達到增加收益等目的，最終造成對病人不利的結果。[按此](#)閱讀相關評論。