

POLICY WATCH
PHARMA

HealthMin plans crowdfunding platform to help treat rare diseases

PRABHA RAGHAVAN
NEW DELHI, JANUARY 13

OVER A year after the government unsuccessfully attempted to finalise a policy for patients with rare diseases, the Health Ministry on Monday announced a reworked draft proposing measures like a crowdfunding platform to finance their costly treatment.

However, groups representing such patients feel the latest draft, which does away with a Rs 100-crore corpus earlier proposed for these often debilitating and lifelong diseases, will have limited impact.

The draft comes a day before the Delhi High Court is expected to hear a case where the government was supposed to submit a national policy on rare diseases.

Rare diseases are often serious, chronic and life-threatening conditions that affect a small number of patients, according to the World Health Organization. This includes haemophilia, spinal muscular atrophy (SMA), cystic fibrosis and Lysosomal Storage Disorders (LSDs).

“Keeping in view the resource constraint and competing health priorities, it will be difficult for the government to fully finance treatment of high cost rare diseases,” stated the latest draft National Policy for Rare Diseases. “The gap can however be filled by creating a digital platform for bringing together notified hospitals where such patients are receiving treatment or come for treatment, on the one hand, and prospective individual or corporate donors willing to support treatment of such patients,” it added.

Treatment cost, often calculated by the body weight of the patient, ranges between Rs 10 lakh and over Rs 1 crore per year for a 10 kg patient, with drug dose and cost increasing with age, states the new draft. The latest document categorises rare diseases into three groups — disorders that can be cured with one-time treatment, diseases requiring long term or lifelong treatment having a “relatively lower cost of treatment” and diseases that require lifelong therapy for which treatment is available but at a “very high cost”.

The policy aims to lower the incidence and prevalence of rare diseases through preventive strategies like screening programmes to prevent births of rare disease children. It also aims to give affordable healthcare to rare disease patients needing one-time treatment, which applies to patients falling under the first category of rare diseases.

It proposes financial support up to Rs 15 lakh under the Rashtriya Arogya Nidhi (RAN) for one-time treatment of patients belonging to below

The draft National Policy for Rare Diseases proposes a digital platform for bringing together notified hospitals with such patients and prospective donors

poverty line (BPL) families as well as 40 per cent of the population eligible under the Pradhan Mantri Jan Arogya Yojana. State governments can consider supporting patients in the second category of rare diseases, managed with special diets, hormonal supplements “or other relatively low cost interventions”. Citing resource constraints, the draft has proposed the “alternate” crowdfunding platform for the third category of diseases.

The government has sought comments on this draft by February 10. Organisation for Rare Diseases India co-founder and director Prasanna Shirol says the limited financial assistance means the policy will benefit only a small portion of rare disease patients. “There is no financial commitment announced, especially for group three diseases like LSDs and SMA. Crowdfunding and donations for such a costly treatment is humanly not possible,” said Shirol. The draft is also not clear about provisions for non-BPL patients, he said.

“The provisions of Rs 15 lakh under RAN for BPL patients was already (being provided), but even this amount may not be enough in some cases. If a patient needs a bone marrow transplantation but none of the family members are a match, they may have to import it, which would increase the cost of treatment over Rs 15 lakh,” he said. “Even if some of my patients with Fabry disease get funding to get their kidney replaced successfully, after that also they will need enzyme replacement therapy for the rest of their life. This is not covered under the policy,” said Manjit Singh, president at Lysosomal Storage Disorder Support Society. The last draft formulated in July 2017 could not be implemented as the Centre was unable to bring states “on board”.

“When the policy was shared with State Governments, issues such as cost effectiveness of interventions for rare disease vis-a-vis other health priorities, sharing of expenditure between central and State Governments, flexibility to State Governments to accept the policy or change it according to their situation, were raised by some of the State Governments,” stated the latest draft.

ONLY ABOUT 50% OF TOP 500 LISTED FIRMS HAVE COMPLIED

Splitting of CMD post: Sebi defers deadline to Apr 2022

ENSECONOMIC BUREAU
MUMBAI, JANUARY 13

IN A big relief to the corporate sector, the Securities and Exchange Board of India (Sebi) has extended the timeline for top 500 listed companies to comply with its new rule, which mandates a split in the post of chairman and managing director of a company and also bars relatives from holding key jobs in a company, by two years to April 2022.

The regulator issued a notification on its website on January 10 extending the timeline. Sebi, in May 2018, asked the top 500 listed companies to split the post of chairman and managing director by April 2020, following the recommendations of the Uday Kotak-led panel on corporate governance.

However, data from stock exchanges reveal that at present, only around 50 per cent of the top 500 listed entities are in compliance with the aforementioned regulatory provision. Sebi has also been receiving various representations with respect to the above regulatory requirement including from industry bodies like Ficci and CII. The representations, seen together with the compliance levels, highlight the present levels of unpreparedness of listed entities to comply with the above regulatory provision, according

Explained: Delaying Apr 2020 target will help lower compliance burden

AT a time when companies are busy working their way around slowdown in the economy to generate growth in revenue and profitability, Sebi’s decision to provide a two-year window to comply with the requirement of splitting the post of chairman and managing director from April 2020 to April 2022 comes as a big relief.

While the order offering relaxation will help ease compliance burden and give them additional time to comply with this regulatory provision, exchange data reveals that at present, only around 50 per cent of the top 500 listed entities are in compliance with the regulatory provision.

to market sources.

Given the above backdrop and considering the current economic scenario, it has been decided that, in order to ease the compliance burden, additional time may be provided to listed entities to comply with this regulatory provision, sources said. Accordingly, the date of implementation of the above regulatory provision has been deferred to April 1, 2022.

Currently, several listed companies have integrated the two positions as CMD (chairman-cum managing director) that overlap the board and the management in some cases, which could cause

conflict of interest.

Meanwhile, Federation of Indian Chambers of Commerce and Industry (Ficci) Monday welcomed Sebi’s decision to extend the deadline. “This was part of multiple representations made by Ficci and we appreciate that Sebi has extended the deadline as managerial continuity, unified vision and speed of execution are crucial to business success and are facilitated in family businesses,” Ficci president Sangita Reddy said.

While Sebi has deferred the implementation of the new norm to 2022, Ajay Tyagi, in November 2019, said the regulator had al-

ready given “sufficient time” to companies to understand the rule and plan for it. “Extending the time (beyond April 2020) will only mean that they (the companies) don’t want to do it,” Tyagi had said.

Among big corporates, only two companies— Mahindra & Mahindra and Wipro Ltd— have moved to implement the guideline on the top posts. Managements of many other large companies, including Reliance Industries Ltd and Bharti Airtel Ltd, are yet to make any moves towards restructuring to comply with Sebi rules.

Section 203 of the Companies Act requires all companies to have a separate Chairperson and MD/CEO unless the Articles of Association of the company provides otherwise. According to Prime Database, a research firm that tracks capital markets, the Chairperson and the MD/CEO are the same in 159 of the top 500 listed companies by market capitalisation.

The regulator’s amendments followed the October 2017 recommendations of the Committee on Corporate Governance chaired by Uday Kotak, which observed the time was right to introduce the separation of roles of Chairperson and MD/CEO of listed entities. In framing the regulations, Sebi went a step ahead and said the two persons should not be related either. **WITH PTI**

‘India may create 15 lakh less jobs this year’

The slowdown has adversely impacted employment generation in the country as over 15 lakh less jobs are projected to be created in FY20 compared to 89.7 lakh fresh jobs in FY19, the SBI Research report ‘Ecowrap’ said

DECLINE IN REMITTANCES in few states like Assam and Rajasthan, reflecting downsizing of contractual labourers

PROJECTION

In FY19, India had created 89.7 lakh new payrolls as per the EPFO data. In FY20, as per current projection, this number could be at least 15.8 lakh lower



REASONS FOR JOB LOSS
The delay in resolution of cases under bankruptcy proceedings may have prompted companies to downsize their contractual labourers

WHERE IS THIS DATA FROM?

■ The EPFO data primarily covers low paid jobs as the salary is capped at ₹15,000 per month. As per the calculation done by the report, during April-October 2019, the actual net new payroll was 43.1

lakh which annualised comes out to be 73.9 lakh for FY20

■ The EPFO data does not cover government jobs, state government jobs and private jobs as such data have moved to

National Pension Scheme (NPS), beginning 2004.

■ Even in the NPS category, state and central government are supposed to create close to 39,000 jobs less in FY20 as per current trends

Source: SBI Research/PTI

CCI initiates probe against Flipkart, Amazon on ‘deep discounting’

AASHISH ARYAN

NEW DELHI, JANUARY 13

THE COMPETITION Commission of India (CCI) on Monday ordered an investigation into alleged malpractices by Flipkart and Amazon India as far as the issue of deep discounting and practice of preferred sellers of mobile phones by both the retailers was concerned.

The anti-trust body ordered the probe on a complaint by Delhi Vyapar Mahasangh, a micro, small and medium scale enterprise (MSME) body, which al-

The anti-trust body ordered the probe on a complaint by Delhi Vyapar Mahasangh, a micro, small and medium scale enterprise body

leged that both the retailers were engaged in deep discounting and preferred selling of mobile phones and related accessories “which have led to a foreclosure of other non-preferred traders or

sellers from these online marketplaces”.

“Amazon with their preferred sellers on the platforms leads to a foreclosure of other non-preferred sellers from the online marketplace. These preferred sellers are also alleged to be affiliated with or controlled by Flipkart/Amazon either directly or indirectly,” the MSME body had said in its complaint to the CCI.

Home-grown retailer Flipkart in its statement said it was fully compliant with “all applicable laws and foreign direct investment regulations” and that it was

focusing on making quality and affordable goods available through its “transparent and efficient marketplace”. Amazon did not respond to media queries till the time of going to press.

The action on Amazon comes two days before its global head Jeff Bezos is scheduled to visit India for a short tour. Bezos will be in India in the same week when Amazon is holding its event ‘Smbhav’ to attract more MSME players on its platform.

In their complaint, the Delhi Vyapar Mahasangh said apart from deep discounting and the practice of appointing nomi-

nated sellers, both the retailers had exclusive tie-ups and private labels, which leave out MSMEs, forcing them to opt for the higher cost brick-and-mortar model.

“Due to huge market base and market power, the opposing parties (Amazon India and Flipkart) have large repositories of data which allow them to target advertisements based on consumer preferences and marginalise other competitors, which are unable to capture the market due to lack of access to data. This has resulted in creation of high entry barriers on account of network effects,” the

MSME body said in its complaint.

The action by the CCI also comes nearly a week after it came out with a report on the key findings and observations of the e-commerce market in India.

In the report, the CCI had flagged that though online commerce had shown increased price transparency and competition, ensuring competition on the merits, increasing transparency to create incentive for competition, and fostering sustainable business relationships between all stakeholders was the immediate need of the hour.

as its former promoters and directors for alleged money laundering.

JSW Steel had been wary of pursuing the resolution plan after the ED had in October started attaching properties worth nearly Rs 4,000 crore, belonging to Bhushan Power. Following the raids, JSW Steel approached the NCLAT, while halting the implementation of the resolution plan, asked ED to release the assets attached by it.

In December 2019, the government amended the Insolvency and Bankruptcy Code (IBC), which bypassed the stand taken by the ED. Article 32(A) of the IBC, introduced via an amendment, provided immunity to successful resolution applicants from any old and ongoing cases against the corpo-

rate debtors. The new amendment also said that there would be no action, including attachment by any agency, against any property of the corporate debtor.

The appellate tribunal, last October, also noted that such actions by agencies like ED, and the CBI or SPIO would “fail” IBC. “IBC cannot be annulled in this manner. Money laundering is by an individual not company,” the appellate tribunal bench had then said.

Though the Committee of Creditors of Bhushan Power requested the NCLAT to lift its stay on the implementation of the plan, the appellate tribunal denied the plea and said that there were several other pleas, including one moved by the former promoters of the corporate debtor.



GOLD

₹40,432



RUPEE

₹70.86



OIL

\$66.34



SILVER

₹47,635

*Indian basket as on January 9, 2020

Centre rolls out disclosure scheme to tag rogue drones

PRANAV MUKUL

NEW DELHI, JANUARY 13

DAYS AFTER a US drone attack killed Iran’s top military commander General Qassem Soleimani, the Civil Aviation Ministry has announced a scheme for voluntary disclosure of “non-compliant” unmanned aerial vehicles (UAVs), or drones, being operated inside India to make up for the lack of a comprehensive database.

“The presence of...drones as well as drone operators has come to the notice of the government, which do not comply with the CAR (civil aviation requirement)...If drones are operated without due permission, the aforesaid process of CAR is violated...In order to facilitate the identification of civil drones and drone operators, a one-time opportunity for voluntary disclosure of such drones and drone operators is now being provided,” the Ministry said in a public notice issued Monday.

Pointing out that the voluntary disclosure scheme was the first step in regulating the drone ecosystem in India, a senior government official told *The Indian Express*: “Some people say there are 6 lakh rogue drones in the country but we don’t know for sure how many such non-compliant drones are being operated, which is why we are conducting this exercise. We want to bring unregistered drones under the fold.”

The government has asked the owners of unregistered drones to submit the required information to the government by January 31.

The Ministry’s notice pointed out that upon successful submission of voluntary disclosure, a Drone Acknowledgement Number (DAN) and an Ownership Acknowledgement Number (OAN) will be issued online. “However, the DAN or OAN does not confer any right to operate drones in India if it does not fulfill the provisions given in the CAR,” it said.

On Friday, *The Indian Express* reported that the Centre is likely to tighten drone regulations in the wake of two major global attacks involving UAVs over the last few months — on Saudi Arabian refineries that impacted nearly half of the country’s global crude supply, and the killing of Soleimani in Baghdad.

The Civil Aviation Ministry

‘Trump to halt civilian drone programme’

Bengaluru: The US government is planning to permanently halt its civilian drone programme due to the devices being made at least partly in China, the *Financial Times* reported on Sunday.

The US Department of the Interior is considering halting about 1,000 drones after deciding that the risk of the drones being used by Beijing for spying was too high, the *FT* report said, citing two people briefed on the plans. Sources also told *FT* that the Secretary of the Interior David Bernhardt has not signed an official policy but is planning to pull the fleet from action, with exceptions for emergencies such as fighting wildfires. **REUTERS**

has finalised the National Counter Rogue Drone Guidelines to lay down an array of counter-rogue measures and guidelines that can be deployed for handling threats to installations from UAVs. The implementation of these guidelines, according to officials, is being expedited in light of the latest developments.

India has a ‘No Permission-No Takeoff’ (NPNT) policy for UAVs, which mandates the drone to be operated only with a regulatory permission received through the Digital Sky Platform. Further, the pilot also needs certification, requiring a remote pilot licence or an unmanned aerial operator permit before operating a drone.

Under regulations issued by the Directorate General of Civil Aviation (DGCA), penalties under the Aircraft Act and the Indian Penal Code have been prescribed for those failing to comply with norms.

“Unregistered drones acquired prior to 2014, when flying of drones was banned in India by the DGCA, are a threat to the country’s security and airspace. We will develop rules as and when technology evolves and would ideally want these aircraft to operate in a regulated manner with a full-fledged flight plan, traffic control, etc,” the government official said.

EXPRESS NEWS SERVICE

NEW DELHI, JANUARY 13

THE SUPREME COURT on Monday gave the go-ahead to the Enforcement Directorate (ED) to attach US-based JP Morgan’s properties in India for allegedly colluding with real estate group Amrapali to divert funds of homebuyers in violation of Foreign Exchange Management Act (FEMA) rules. The ED, had in its submission, told the apex court that it had “prima facie” found violation of FEMA by JP Morgan.

ED Joint Director Rajeshwar Singh told a Bench of Justice Arun Mishra and Justice U U Lalit that a complaint had been lodged regarding this.

The Bench also asked the agency to take Amrapali CMD Anil Kumar Sharma and its two directors, Shiv Priya and Ajay Kumar, to investigate money-laundering charges.

Singh told the Bench that the adjudication process against JP Morgan had already begun.

The ED had told the court last year about the alleged FEMA violations and that it had recorded the statement of the company’s country head in this regard.

The agency also said it suspected violation of the Prevention of Money Laundering Act (PMLA).

Deciding a petition filed by homebuyers who had invested in around 42,000 flats of the Amrapali Group, the apex court, in July last year, cancelled its RERA registration.

The court said it was apparent

from the report of the forensic audit submitted by Forensic Auditors that there is a serious kind of fraud played upon the buyers in active connivance with the officials of the Noida and Greater Noida Authorities and that of the banks. The money of the homebuyers has been diverted.

“The Directors diverted the money by the creation of dummy companies, realising professional fees, creating bogus bills, selling flats at undervalue price, payment of excessive brokerage, etc. They have obtained investment from JP Morgan in violation of FEMA and FDI norms. The shares were overvalued for making payment to JP Morgan. It was adopted as a device for siphoning off the money of the homebuyers to foreign countries,” the court said.

ENS ECONOMIC BUREAU

NEW DELHI, JANUARY 13

THE NATIONAL Company Law Appellate Tribunal (NCLAT) on Monday asked the Enforcement Directorate (ED) and the Ministry of Corporate Affairs (MCA) to file affidavits clarifying that JSW Steel, which placed the winning bid for Bhushan Power & Steel, will not be persecuted for financial irregularities allegedly committed by former promoters of the company.

If the probe agencies wanted to continue pursuing Bhushan Power in their case of money laundering, they must explain the reasons for the same, the NCLAT said.

The MCA will file the affidavits on behalf of Serious

NCLAT ASKS PROBE AGENCIES TO BE SPECIFIC

■ If the probe agencies wanted to continue pursuing Bhushan Power in their case of money laundering, they must explain the reasons for the same, the NCLAT said

■ The MCA will file the affidavits on behalf of Serious Fraud Investigation Office (SPIO) and the

Central Bureau of Investigation, latest by January 20, the Bench said

■ JSW Steel, which at Rs 19,700 crore had placed the winning bid for Bhushan Power & Steel, had been wary of proceeding with the resolution plan owing to cases pending against the latter

Fraud Investigation Office (SPIO), and the Central Bureau of Investigation, latest by January 20, a three-member Bench led by Chairperson Justice S J Mukhopadhyaya said.

JSW Steel, which at Rs 19,700 crore had placed the

winning bid for Bhushan Power & Steel, had been wary of proceeding with the resolution plan owing to cases pending against the latter. This was after the ED had remained firm on its idea to attach the properties of Bhushan Power, as well