# The Baily Star



Saving a few minutes is more important to this biker than his own safety as he was driving on the wrong side of the road to avoid the gridlock on the other side. As a result, a car coming from the opposite direction bumped into the motorcycle slightly. A serious accident was avoided and the rider was left with only a few scratches, as the car managed to hit the brakes right at the last second. This photo was taken in Shikkha Bhaban area yesterday.

## 'Bring back order at the grassroots'

Local AL leaders urge new leadership after national council

ASHIK ABDULLAH APU

Leaders and activists of the Awami League's grassroots level said they expect the new AL leadership, elected through the 22nd national council yesterday, will play a strong role in organising the fieldlevel workers ahead of the next national

They Daily Star talked with at least 12 councillors and delegates attending the national council. They said they want the AL leadership to work to strengthen the party base at the grassroots and help Prime Minister Sheikh Hasina build "Smart Bangladesh".

Netrakona Jubo Mohila League general secretary and councillor Syeda Shamsunnahar Beauty told The Daily Star, 'We want a strong and committed general secretary who will face the challenges of the next national election."

"Ahead of the elections, we need a leader who can organise the grassrootslevel workers. We know that the decision of the prime minister is final, but we also want her to pick a leader who will organise the grassroots," she added.

The national council of the ruling AL

was held at the historic Suhrawardy Udyan in the capital.

Jamal Uddin Mahi, a member of the AL's religious affairs subcommittee, said, "We also want young leadership to continue the progress of our prosperity under the leadership of the prime minister. We hope that our leadership will be a combination of both junior and senior leaders, who will make it possible to implement Sheikh Hasina's Vision 2041."

"The top leadership [of Awami League] often overlooks the politics and politicians, which is why there is a chaotic situation that prevails in many grassroots level committees. Local leaders pick their 'man' in the leadership. We want the new committee to work for bringing back order in the grassroots," a grassroot-level Shwecchhashebak leader from Bhola told The Daily Star.

Sved Abdul Kafi, 90, former education and human resource affairs secretary of Cumilla city (south), said he wants the general secretary to travel across the country and unite the field-level activists.

Azizul Haque, a freedom fighter and a delegate of the council, said the main

#### No alternative to Hasina

#### **Says Quader**

STAFF CORRESPONDENT

Re-elected Awami League General Secretary Obaidul Quader yesterday said Awami League and Prime Minister Sheikh Hasina should be brought to power again for the welfare of the country.

must Awami League to save Bangladesh," he said while presenting the general secretary's report at the first session of the AL's 22nd national council at the historic Suhrawardy Udyan in the city.

Quader, also road transport a n d bridges minister, urged all

forces to be united and said, "There is no alternative to Sheikh Hasina...'

"No matter how many disasters and catastrophes came (in the country), we will always be beside people. It's our commitment to stand by the country's people," he also said.

Referring to BNP, Quader said, "BNP leaders think that if Sheikh Hasina government is toppled, all the defeated forces will come to power. But that will not happen. They could not do so on December 10. We are ready to face them."

He said Hasina has been the most popular, courageous, and efficient  $administrator\, and\, diplomat$ in the last 47 years. Hasina is the troubleshooter and there is no alternative to her, he said.

#### 7 inter-district robbers held

BSS, Dhaka

The Rapid Action Battalion (Rab-4) claimed to have arrested seven members of an inter-district gang of robbers with stolen garments products worth Tk 5 crore in the Demra area early yesterday.

The arrestees are Md Tawhidul Kaushar, 42, Md Nazim, 35, Md Masud, 35, Md Dulal, 45, Md Miraj Uddin, 33, Abdul Al Masud, 30, and Md Saiful Islam, 22, said Rab officials.

Lt Col Mohammad Abdur Rahaman, commanding officer (captain) of Rab-4, told the news agency that acting on a tip-off, a team of Rab-4 arrested them in the Demra area. The officials also seized a covered van filled with a large number of exportable clothing items.

A process is underway to take necessary action against them, the official

## The unheard plight of those with rare diseases

Amid dearth of treatment options, patients suffer due to misdiagnosis, lack of awareness

MOUDUD AHMMED SUJAN

In 2014, Iraboti Roy, 40, a patient with the disease Myasthenia Gravis, died a day after a doctor in the country's top neurological hospital used a sedative on her.

Myasthenia Gravis is a rare, long-term condition that causes severe muscle weakness and often remains undetected in patients, leading to misdiagnosis and wrong treatment.

"Had the doctor not jabbed her with that injection, my sister could have survived. But I would not blame the physician because most doctors are unaware of rare diseases present in the country," said Shashanka Baran Roy, Iraboti's brother.

Myasthenia Gravis is one of approximately 7,000 rare diseases discovered so far. These conditions affect the lives of around 300 million people worldwide at any time, according to Global Genes -- a US-based organisation that works for individuals and families fighting rare and genetic diseases.

Being rare, there is a lack of awareness among physicians about these diseases, and medication to treat them is not widely available, leaving patients helpless.

For instance, Jakia Abedin, a 36-year-old Myasthenia Gravis



#### **THE PROBLEMS**

- >> Lack of awareness among doctors
- >> Medication expensive, not widely available
- >> No govt policy, fund
- >>> Arrangement for diagnosis inadequate
- >>> Flaws in educational curriculum

Absence of referral system

discouraged me from discussing my illness, assuming that it was all in my head. Later, physicians too made mistakes time and again. Throughout this time, I was the one who suffered. SUMONA MONZUR

Who has Myasthenia Gravis

Initially, my parents even

We have highly qualified physicians, but access to them is an issue. Besides, even the country's top hospitals often lack state-of-the-art technology for diagnosis.

> PROF MOHAMMAD HOSEN Dean of neurosurgery faculty at BSMMU

patient in Munshiganj, lost two babies just days after giving birth to them in 2006 and 2014.

Before conceiving the second child, Jakia asked her doctor in Munshigani all alone. She Myasthenia Gravis patient in medicines for her rare illness but 1999 -- whether her disease was cannot afford the regular doses. responsible for the death of her

"My doctor told me there was no connection. But now I would have lived if we had taken through surgery, which her

precautionary measures," Jakia told The Daily Star.

Abandoned by her husband, Jakia, now lives in a rented house who first identified her as a needs Tk 4,000 a month to buy

"I take medicine only when I need to move from my bed," said Jakia between her sobs.

Jakia's life could be easier if know there was and my baby her thymus gland were removed

doctor advised back in 2004. But she could not manage the required amount -- between Tk

2 to Tk 10 lakh -- for her surgery. Amid the absence of policy and government funds, many patients with Myasthenia Gravis and other rare diseases lead a miserable life in Bangladesh, where out-ofpocket expenditure for treatment is 68.5 percent of the total cost.

Meanwhile, nine-year-Anisur Rahman has SEE PAGE 4 COL 6

### **HIGH COURT BAIL** Fakhrul, Abbas may have to wait 8 more days

ASHUTOSH SARKAR

BNP Secretary General Mirza Fakhrul Islam Alamgir and the party's Standing Committee



member Mirza Abbas may have to wait for at least eight more days to seek bail from the High Court in the case filed over the December 7 clash between party activists and police.

The High Court is scheduled to reconvene on January 2 after its ongoing annual vacation.

Mirza Fakhrul and Mirza Abbas, who have been denied bail four times by the lower courts concerned in the case, have scope to seek bail from Dhaka court and the High Court.

On December 21, Judge Md Asaduzzaman of Dhaka Metropolitan Sessions Judge Court rejected their bail petitions, and also fixed January 25 next year for hearing the petitions.

Advocate Zainul Abedin, a senior lawyer for ne accused BNP leaders, told The Daily Star on December 24 that they are yet to receive the copies of the bail petition rejection orders of Mirza Fakhrul Islam Alamgir and Mirza Abbas in

"After getting the certified copies, we will decide whether we will move petitions before the Dhaka Metropolitan Sessions Judge Court again or High Court seeking bail for the detained BNP leaders. We will take the decision when the High Court and Dhaka judge court will reopen following their ongoing vacation," he said.

Contacted, BNP's Legal Affairs Secretary Kayser Kamal told this correspondent, "Unfortunately their [Fakhrul and Abbas] bail petitions were rejected despite not being named accused in the FIR [first information report]."

"Political motivation and consideration are

SEE PAGE 4 COL 1

### TEKNAF, UKHIA Govt building 50 cyclone shelters

BSS, Dhaka

The government is building a total of 50 multipurpose cyclone shelters and schools under the Emergency Multi-Sector Rohingya Crisis Response Project (EMCRP) at Teknaf and Ukhia upazilas in Cox's Bazar

Under the project, the government is also building and improving relief administration and distribution centres, multipurpose community service centres, bazaars, firefighting warehouses, roads, footpaths, drains, culverts, bridges, lightning arresters and installs solar street lights inside the camps, said a press

EMCRP, aided by the World Bank, was launched to provide greater protection for the around 11.00 lakh





BHALO KAAJER HOTEL (MEAL FOR A GOOD DEED)... Dozens of people were sitting on the footpath and enjoying their afternoon meal -- khichuri with egg curry -- at this strange "restaurant" that does not charge customers. One simply needs to do one good deed a day to get food from here. The place mainly provides food to those afflicted with poverty, who cannot afford three square meals a day. This photo was taken in Tejgaon area yesterday.