

Press Coverage Clippings of ORDI's Race for 7 Events



Spreading the word



Medical Education Minister K. Sudhakar flagging off 'Race for 7', a run to create awareness on the challenges of rare disease patients and their families, in Bengaluru on Sunday. Tejasvi Surya, MP, was present.

ಅಪರೂಪದ ರೋಗಿಗಳ ಬೆಂಬಲಕ್ಕೆ ಬೆಂಗಳೂರು

ಸಂ.ಕ. ಸಮಾಚಾರ ಬೆಂಗಳೂರು ಭಾರತದಲ್ಲಿ 70 ಮಿಲಿಯನ್ ಅಪರೂಪದ ರೋಗಿಗಳು ಇದ್ದಾರೆಂದು ನಾವು ನಿರೀಕ್ಷಿಸಲು ಸಾಧ್ಯವಿಲ್ಲ. ಅಪರೂಪದ ರೋಗ ಸಮುದಾಯಕ್ಕೆ ಹೆಚ್ಚು ಅಂತರ್ಗತ ಸಮಾಜವನ್ನು ರಚಿಸಲು ನಾವೆಲ್ಲರೂ ಒಟ್ಟಾಗಿ ಕೆಲಸ ಮಾಡಬೇಕಾಗಿದೆ ಎಂದು ವೈದ್ಯಕೀಯ ಶಿಕ್ಷಣ ಸಚಿವ ಡಾ. ಕೆ. ಸುಧಾಕರ್ ತಿಳಿಸಿದ್ದಾರೆ.



ಮಾತನಾಡಿ, ಅಪರೂಪದ ರೋಗಿಗಳಿಗೆ 70ರಷ್ಟು ಪ್ರಾರಂಭವಾಗುತ್ತದೆ. 30ರಷ್ಟು ಮಂದಿ ಮೊದಲೇ ಸಾವನ್ನಪ್ಪಿರುತ್ತಾರೆ. ಅಪರೂಪದ ರೋಗಿಗಳಿಗೆ ಕಾಳಜಿ ವಹಿಸಿ ಎಲ್ಲರಿಗೂ ಆಗಬೇಕು. ಈ ಕಾರ್ಯಕ್ರಮದ ಆರ್. ಪ್ರಸಾದ್, ಒಳ ನಿರ್ದೇಶಕ ಪ್ರಸನ್ನ ತಿರುಮಲಾ, ಐಕ್ಯವಿವಿ ನಿರ್ದೇಶಕ ಅಮಿತ್ ಕುಮಾರ್, ಪೆನಿಟೆನ್ಸ್ ಸಿಬ್ಬಂದಿ ಮೀನಾಕ್ಷಿ ಭಟ್, ಐಕ್ಯವಿವಿ ನಿರ್ದೇಶಕ ವಾನ್ ಭಾ

ಅಪರೂಪದ ರೋಗ ಸಮುದಾಯಕ್ಕೆ ಜಾಗೃತಿ ಮೂಡಿಸಲು ಆರ್ಗನೈಸೇಶನ್ ಫಾರ್ ರೇರ್ ಡಿಸೀಸ್ ಭಾರತ ವತಿಯಿಂದ ಏರ್ಪಡಿಸಲಾಗಿದ್ದ ಓಟದ ಕಾರ್ಯಕ್ರಮಕ್ಕೆ ಚಾಲನೆ ನೀಡಿ ಮಾತನಾಡಿದ ಅವರು, ಜಾಗತಿಕವಾಗಿ 350 ಮಿಲಿಯನ್ ರೋಗಿಗಳು, ಇದರಲ್ಲಿ 70 ಮಿಲಿಯನ್ ಅಪರೂಪದ ರೋಗಿಗಳು ಭಾರತದಲ್ಲಿದ್ದಾರೆ. ಇಂತಹ ರೋಗವನ್ನು ಪತ್ತೆ ಹಚ್ಚಬೇಕಾದರೆ ಏಳು ವರ್ಷ ತಪಾಸಗೆ ಮಾಡಬೇಕಾಗುತ್ತದೆ. ಇಂತಹ ರೋಗ ಬಂದಲ್ಲಿ ಆದಕ್ಕೆ ಬಹುತೇಕರಿಗೆ ಚಿಕಿತ್ಸಾ ವೆಚ್ಚವನ್ನು ಭರಿಸಲು ಸಾಧ್ಯವಾಗುವುದಿಲ್ಲ. ಇದರಿಂದಾಗಿ ಮುನ್ನೆಚ್ಚರಿಕೆ ಕ್ರಮವಾಗಿಯೇ ಇಂತಹ ಕಾಯಿಲೆಗಳನ್ನು ತಡೆಗಟ್ಟಬೇಕಾಗುತ್ತದೆ ಎಂದರು. ಸಂಸದ ತೇಜಸ್ವಿ ಸೂರ್ಯ

The Hindu

ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಜಾಗೃತಿಗಾಗಿ ರೇಸ್

ಬೆಂಗಳೂರು: ಅಪರೂಪದ ಕಾಯಿಲೆಗಳನ್ನು ಕುರಿತು ಜಾಗೃತಿ ಮೂಡಿಸಲು ಆರ್ಗನೈಸೇಷನ್ ಫಾರ್ ರೇರ್ ಡಿಸೀಸ್ ಇಂಡಿಯಾ ಸಂಸ್ಥೆ ಪತಿಯಿಂದ ರೇಸ್ ಫಾರ್ 7 ಎಂಬ ಕಾರ್ಯಕ್ರಮವನ್ನು ಆಯೋಜಿಸಲಾಗಿತ್ತು. ಕಾರ್ಯಕ್ರಮಕ್ಕೆ ಸಂಸದ ತೇಜಸ್ವಿ ಸೂರ್ಯ ಅವರು ಹಾಜರಿ ನಿಶಾನೆ ಕೋರಿಸುವ ಮೂಲಕ ಓಟಕ್ಕೆ ಚಾಲನೆ ನೀಡಿದರು. ನಗರದ ನೂರಾರು ಮಂದಿ ನಾಗರಿಕರು ಈ ಓಟದಲ್ಲಿ ಭಾಗವಹಿಸಿ ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಬಗ್ಗೆ ಜನಜಾಗೃತಿ ಮೂಡಿಸಿದರು. ಭಾರತೀಯರಲ್ಲಿ ಅಂದಾಜು 20 ವ್ಯಕ್ತಿಗಳಲ್ಲಿ ಒಬ್ಬ ವ್ಯಕ್ತಿ ಅಪರೂಪದ ಕಾಯಿಲೆಗಳಲ್ಲಿ ಬಳಲುತ್ತಿದ್ದಾರೆ. ಅವರಿಗೆ ಅರಿವು ಮತ್ತು ಮಾಹಿತಿ ಕೊರತೆ ಇದೆ. ಸಮಾಜಗಳನ್ನು ಎದುರಿಸಬೇಕಾಗಿದೆ ಎಂದು ಓಟಗಾರರು ತಿಳಿಸಿದರು.



ಸೆಂಟ್ ಜೋಸೆಫ್ಸ್, ಇಂಡಿಯನ್ ವೃದ್ಧ ಕಾಲನಿಯಲ್ಲಿ ನಡೆದ ರೇಸ್ ಫಾರ್ 7 ಓಟಕ್ಕೆ ಸಂಸದ ತೇಜಸ್ವಿ ಸೂರ್ಯ ಚಾಲನೆ ನೀಡಿದರು, ಈ ಸಂದರ್ಭದಲ್ಲಿ ನಟಿ ಕ್ಷೇತಾ, ಆರ್.ಪ್ರಸಾದ್ ಮತ್ತಿತರರು ಇದ್ದರು. ಅಪರೂಪದ ಕಾಯಿಲೆಯನ್ನು ತಿಳಿಸಿದರು. ಅಪರೂಪದ ಕಾಯಿಲೆಯನ್ನು ಯೋಗದಿಂದವರನ್ನು ಸಮಾಜ ಮತ್ತು ಸರ್ಕಾರ ಅರ್ಥ ಮಾಡಿಕೊಳ್ಳಬೇಕಾಗಿದೆ ಎಂದು ದಕ್ಷಿಣ ಏಷ್ಯಾದ ಐಕ್ಯವಿವಿ ವೈಮಾನ್ಯನ ನಿರ್ದೇಶಕ ಅಮಿತ್ ಮುಖರ್ಜಿ ತಿಳಿಸಿದರು. ಈ ಸಂದರ್ಭದಲ್ಲಿ ನಟಿ ಕ್ಷೇತಾ ಆರ್. ಪ್ರಸಾದ್, ಐಕ್ಯವಿವಿ ಓಟಗಾರರು ಒಳಗಡೆ ವಾನ್ ಡಾಡ್ ಇದ್ದರು.

Vishwavani

Samyuktha Karnataka

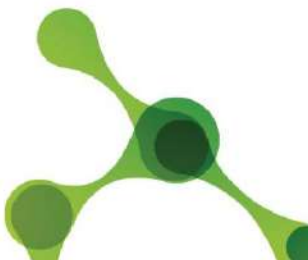
ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಜಾಗೃತಿಗೆ ನಡಿ

ವಿಕ ಸುದ್ದಿಯೊಂದು ಮುನ್ನವೇ ಸೆಂಟ್ ಜೋಸೆಫ್ಸ್ ಇಂಡಿಯನ್ ವೃದ್ಧ ಕಾಲನಿಯಲ್ಲಿ ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಬಗ್ಗೆ ಜಾಗೃತಿ ಮೂಡಿಸುವ ಉದ್ದೇಶದಿಂದ ರೇಸ್ ಫಾರ್ 7 ಎಂಬ ಕಾರ್ಯಕ್ರಮವನ್ನು ಆಯೋಜಿಸಲಾಗಿತ್ತು. ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ರೋಗ ಸಮುದಾಯಕ್ಕೆ ಜಾಗೃತಿ ಮೂಡಿಸಲು ಆರ್ಗನೈಸೇಷನ್ ಫಾರ್ ರೇರ್ ಡಿಸೀಸ್ ವತಿಯಿಂದ 'ರೇಸ್ ಫಾರ್ 7' ಅನ್ನು ಆಯೋಜಿಸಲಾಗಿದೆ. ಸಚಿವ ಡಾ.ಕೆ.ಸುಧಾಕರ್, ಸಂಸದ ತೇಜಸ್ವಿ ಸೂರ್ಯ, ನಟಿ ಕ್ಷೇತಾ ಆರ್.ಪ್ರಸಾದ್ ಸೇರಿದಂತೆ ಹಲವು ಗಣ್ಯರ ಸಮ್ಮುಖದಲ್ಲಿ ನಡೆದ ಚಾಲನೆ ನೀಡಲಾಯಿತು. ಭಾರತೀಯರಲ್ಲಿ ಅಂದಾಜು 20 ವ್ಯಕ್ತಿಗಳಲ್ಲಿ ಒಬ್ಬರು ಅಪರೂಪದ ಕಾಯಿಲೆಗಳಿಂದ ಬಳಲುತ್ತಿದ್ದಾರೆ. ಅವರಿಗೆ ಅರಿವು ಮತ್ತು ಮಾಹಿತಿ ಕೊರತೆಯಿದೆ. ಈ ಸಮಾಜಗಳನ್ನು ಎದುರಿಸ



ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ರೋಗ ಕುರಿತು ಜಾಗೃತಿ ಮೂಡಿಸಲು ಆಯೋಜಿಸಿದ್ದ 'ರೇಸ್ ಫಾರ್ 7' ಸಂದರ್ಭದಲ್ಲಿ ಭಾಗವಹಿಸಿದ್ದ ಐಕ್ಯವಿವಿ ನಡೆದ ಚಾಲನೆ ಎಂದು ಮಾತನಾಡಿದರು. ಬೇಕಾಗಿದೆ ಎಂದು ಮಾತನಾಡಿದರು. ಬಾಲ್ಯದಿಂದ, ಫಲಗಳನ್ನು ಹಿಡಿದು ಪಾಲು ಪಡೆದುಕೊಳ್ಳುವ ಅರಿವು ಮೂಡಿಸಿದರು. ಸಂಸ್ಥೆಯ ಸಂಸ್ಥಾಪಕ ನಿರ್ದೇಶಕ ಪ್ರಸನ್ನ ತಿರುಮಲಾ ಮಾತನಾಡಿ, "ಅಪರೂಪದ ಕಾಯಿಲೆಗಳನ್ನು ಹೊಂದಿದ್ದ ತೇ.50ರಷ್ಟು ಮಕ್ಕಳಿದ್ದಾರೆ. ಅವರ ಜೀವನ ಮಟ್ಟವನ್ನು ಸುಧಾರಿಸಬೇಕಿದೆ. ಆರಂಭಿಕ ಹತ್ತಿ ಮತ್ತು ಚಿಕಿತ್ಸೆ ನೀಡಬೇಕಿದೆ," ಎಂದು ಹೇಳಿದರು. ದಕ್ಷಿಣ ಏಷ್ಯಾದ ಐಕ್ಯವಿವಿ ಪ್ರವಸ್ಥಾನ ನಿರ್ದೇಶಕ ಅಮಿತ್ ಮುಖರ್ಜಿ ಮತ್ತಿತರರು ಇದ್ದು ಸೆಂಟ್ ಜೋಸೆಫ್ಸ್ ಇಂಡಿಯನ್ ವೃದ್ಧ ಕಾಲನಿಯಿಂದ ಆರಂಭವಾದ ಈ ಗಮನ ಕಲ್ಪನಾಪಾಠ್ಯ ಮಾರ್ಗವಾಗಿ ಕೆ.ಮೀ. ದೂರದವರೆಗೆ ಸಾಗಿತು. ವಲೆ ಕೆಲ ಏಕೋಪಚಾರರು ಇದ್ದು ಚೀರ್ಸ್ ಹಾಕಿ ಕೂಡು ನಡೆದಿಗಿಂತ ಸಾಗಿದ್ದು ಗಮನಸೆಳೆಯಿತು.

Viajaya Karnataka





ಬೆಂಗಳೂರು: ಅಪರೂಪದ ರೋಗ ಸಮುದಾಯಕ್ಕೆ ಜಾಗೃತಿ ಮೂಡಿಸಲು ಅರ್ಗನೈಸೇಷನ್ ಫಾರ್ ರೇರ್ ಡಿಸೀಸ್ ಭಾರತ (ಐರ್ಟಿಐ) ದಿಂದ ಪ್ರಾರಂಭಿಸಲ್ಪಟ್ಟ ರೇಸ್ ಫಾರ್ 7 ಅನ್ನು ಇಂದು ಬೆಂಗಳೂರಿನಲ್ಲಿ ಆಯೋಜಿಸಲಾಗುತ್ತದೆ. ಶ್ರೀ ತೇಜಸ್ವಿ ಸೂರ್ಯ, ಸಂಸದರು ಮತ್ತು ಶ್ರೀಮತಿ ಪ್ರೀತಾ ಆರ್. ಪ್ರಸಾದ್, ನಟ ಮತ್ತು ಏಕಶ್ಯೂಟಿಂಗ್ ವಿಭಾಗದ ನಿರ್ದೇಶಕರಾದ ಶ್ರೀ ಪಾನ್ ಡಾಡ್ ಅವರು ಫ್ರಾನ್ಸ್ ತೋರಿಸುವ ಮೂಲಕ ಈ ಓಟಕ್ಕೆ ಚಾಲನೆ ನೀಡಿದರು. ಮತ್ತು ನೂರಾರು ಬೆಂಗಳೂರಿಗರೊಂದಿಗೆ ಸೇರಿಕೊಂಡರು, ಅವರು ಕೇರ್ ಫಾರ್ ರೇರ್ ತೋರಿಸಲು ಓಟದಲ್ಲಿ ಭಾಗವಹಿಸಿದರು. ವಿಶ್ವದ ಅಪರೂಪದ ಕಾಯಿಲೆಗಳಿಗೆ ಸಂಬಂಧಿಸಿದ ರೋಗದ ಘಟನೆಯಾದ ರೇಸ್ ಫಾರ್ 7, 7000 ಅಪರೂಪದ ಕಾಯಿಲೆಗಳನ್ನು ಸಾಂಕೇತಿಕವಾಗಿ ಪ್ರತಿನಿಧಿಸುತ್ತದೆ, 7000 ಜನರು 7 ಅಪರೂಪದ ರೋಗ ಓಟದಲ್ಲಿ ಅಪರೂಪದ ಕಾಯಿಲೆಯನ್ನು ಪತ್ತೆಹಚ್ಚಲು ಸಹಾಯಕರಾಗುವ ಸಲಾಸರಿ ವರ್ಷಗಳನ್ನು ಪ್ರತಿನಿಧಿಸಿದ್ದಾರೆ.

ಪ್ರಸನ್ನ ತಿರೋಲ್, ಸ್ವಾಭಿಕ ನಿರ್ದೇಶಕರು, ಓಟದ ಅಪರೂಪದ ರೋಗ ರೋಗಿಯ ತಂದೆಯಾಗಿದ್ದಾರೆ. "ಎಲ್ಲಾ ಅಪರೂಪದ ರೋಗಿಗಳಲ್ಲಿ 50% ಮಕ್ಕಳು. ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಬಗ್ಗೆ ಜಾಗೃತಿ ಮೂಡಿಸುವ ಮತ್ತು ಇಂತಹ ಪ್ರಯತ್ನಗಳನ್ನು ಬೆಂಬಲಿಸುವ ಅಗತ್ಯವನ್ನು ಅನೇಕರು ತಿಳಿದಿಲ್ಲ. ಜಾಗೃತಿಯಿಂದ ಆರಂಭಿಕ ರೋಗನಿರ್ಣಯ ಮತ್ತು ಚಿಕಿತ್ಸೆಯು ಅವರ ಜೀವಿತಾವಧಿ ಮತ್ತು ಜೀವನದ ಗುಣಮಟ್ಟವನ್ನು ಹೆಚ್ಚಿಸುತ್ತದೆ. ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಬಗ್ಗೆ ವ್ಯಾಪಕವಾದ ಅರಿವಿನ ಮೊದಲನೆಯದಾಗಿ ಆರಂಭಿಕ ಪತ್ತೆ ಮತ್ತು ಚಿಕಿತ್ಸೆಯು ಕೊಡತೆಯ ಜೊತೆಗೆ, ಒಬ್ಬನಿರುವ ಕಡೆಗಳಲ್ಲಿ ಚಿಕಿತ್ಸೆಯು ಹೆಚ್ಚು ಬಹಳ ಮಜಾಬಂದಾಗಿದೆ. ಅಪರೂಪದ ರೋಗಿಗಳಿಗೆ ಹೆಚ್ಚು ಅರಿತುಗಳ ವಾತಾವರಣವನ್ನು ಸೃಷ್ಟಿಸಲು ನಮಗೆ ಬೆಂಬಲ ನೀಡುವ ಅಪರೂಪದ ರೋಗ ನಿವಾರಣಾ ಫೌಂಡೇಷನ್ ಸಂಸ್ಥೆಗಳು, ಶಾಲೆ ಮತ್ತು ಕಾಲೇಜುಗಳ ಸಹಾಯ ತಗಲುವಾಗಿದೆ" ಎಂದು ಅವರು ಹೇಳಿದರು.

Ee Sanje

ಅರುದ್ದಿನ ವ್ಯಾಧುಲನು ಅದುಪು ಚೆದ್ದಾಂ

ಬೆಂಗಳೂರು (ಬೆಂಗಳೂರು), ಹಿನ್ನೆಲೆ: ಅನೇಕ ವ್ಯಾಧುಲನು ಗುರುತಿಸಿದ ಅಗುಲಿ ಕುಟುಂಬದವರು 7 ಓಟದ ಪ್ರಯತ್ನವನ್ನು ಮಾಡಿ ಅದುಪು ಚೆದ್ದಾಂ. ಲೇವಿ ನಿಲುವು ಹಿನ್ನೆಲೆಯಲ್ಲಿ ಅವರು ಧೀರವಾಗಿ ಅನೇಕ ವ್ಯಾಧುಲನು ಗುರುತಿಸಿದರು. 7000 ಜನರು 7 ಅಪರೂಪದ ರೋಗ ಓಟದಲ್ಲಿ ಅಪರೂಪದ ಕಾಯಿಲೆಯನ್ನು ಪತ್ತೆಹಚ್ಚಲು ಸಹಾಯಕರಾಗುವ ಸಲಾಸರಿ ವರ್ಷಗಳನ್ನು ಪ್ರತಿನಿಧಿಸಿದ್ದಾರೆ.



ಬೆಂಗಳೂರಿನಲ್ಲಿ ಅನೇಕ ವ್ಯಾಧುಲನು ಗುರುತಿಸಿದರು.



ಬೆಂಗಳೂರಿನಲ್ಲಿ ಅನೇಕ ವ್ಯಾಧುಲನು ಗುರುತಿಸಿದರು.



ಬೆಂಗಳೂರಿನಲ್ಲಿ ಅನೇಕ ವ್ಯಾಧುಲನು ಗುರುತಿಸಿದರು.



ಬೆಂಗಳೂರಿನಲ್ಲಿ ಅನೇಕ ವ್ಯಾಧುಲನು ಗುರುತಿಸಿದರು.

Ee Naadu

ರೇಸ್ ಫಾರ್ 7: ಚಾಲನೆ-ತೇಜಸ್ವಿ ಸೂರ್ಯ, ಆಯೋಜನೆ-ಒಆರ್‌ಡಿ, ಸ್ಥಳ-ಸೇಂಟ್ ಜೋಸೆಫ್ ಪ್ರೌಢಶಾಲೆ, ಮಲ್ಲ ಆಸ್ಪತ್ರೆ ಹತ್ತಿರ, ಬೆಳಿಗ್ಗೆ 6.30

Prajavani



ಬೆಳಿಗ್ಗೆ
ಆರ್ಗನೈಸೇಷನ್ ಫಾರ್ ರೇರ್ ಡಿಸೀಸ್
ಇಂಡಿಯಾ: 'ರೇಸ್ ಫಾರ್ 7' ನಡಿಗೆ ಕಾರ್ಯಕ್ರಮ. ಆತಿಥಿಗಳು: ಸಂಸದ ತೇಜಸ್ವಿ ಸೂರ್ಯ, ಸ್ಥಳ: ಸೇಂಟ್ ಜೋಸೆಫ್ ಇಂಡಿಯನ್ ಹೈಸ್ಕೂಲ್, ಮಲ್ಲ ಆಸ್ಪತ್ರೆ ಹತ್ತಿರ. 6.30

Vijaya Karnataka





ಸಂಕಲನ ಚಿತ್ರ: ಕ್ಯಾನ್ಸರ್ ಛೇದನಾಚರಣೆ ಮತ್ತು ಸಂಶೋಧನಾ ಕ್ರಮಗಳನ್ನು ಪ್ರೋತ್ಸಾಹಿಸಲು ದಿವ್ಯಾ ಲಯದ ಹಳೆಯ ದಿವ್ಯಾ ಛೇದನಾ ಸಂಘದ ಅಧ್ಯಕ್ಷಿಣಿ ಛೇದನಾಚರಣೆ ಆಯೋಜಿಸಿದ ಅನೇಕವಾರದ ಕಾರ್ಯಕ್ರಮ ಮತ್ತು ಕ್ಯಾನ್ಸರ್ ಚಿಕಿತ್ಸೆ ದಾಖಲೆಗಳಿಗೆ ದೈವ ಶಕ್ತಿಯು ತಿಳಿದು ಸಹಾಯ ಮಾಡಿತು. ಕೆ.ಸುಧಾಕರ್ ಚಾಲನೆ ನೀಡಿದರು. ಬೆಂಗಳೂರು ವಕ್ರಾ ರೋಗಾಣು ಕೇಂದ್ರದ ಸಂಪದ ಕೇಂದ್ರ, ಕೂಡಿಯಾ, ದಿವ್ಯವಿಷಿ ಆಯುಷ್ಯ ಕೂಡು. ದಿ.ಎಸ್. ಅನೇಕ ಕುಟುಂಬದ ಸಂಪ್ರದಾಯ.

ಆರೋಗ್ಯಾನಿಗೆ ವಾಕಧಾನ್



ವಾಕಧಾನ್ ಪ್ರಾರಂಭಿಸುನ್ನ್ ದೃಶ್ಯಂ

ಬನಶಂಕರಿ: ರೋಗಾಲ ವಟ್ಟ ಜಾಗೃತಂ ಚೆಯಡಾ ನಿಕಿ ಆದಿವಾರಂ ನಗರಂಲೊನಿ ಸೆಯಿಂಟ್‌ಜೊ ಸೆಫ್ ಇಂಡಿಯನ್ ಸ್ಕೂಲ್‌ಲೊ ವಾಕಧಾನ್ ನಿರವ್ವಹಿಂಚಾರು. ವೈದ್ಯವಿದ್ಯಾಸಾಖ್ಯಾಂಮಂತ್ರಿ ಡಾಕ್ಟರ್ ಸುಧಾಕರ್, ಎಂಪಿ ತೆಜಸ್ವಿ ಸುರೈ, ನಟಿ ಶೈಲಾ ಆರ್.ಪ್ರಸಾದ್ ತದಿತರುಲು ಜೆಂಡಾ ಡಿಪಿ ಪ್ರಾರಂಭಿಂಚಾರು.

Release ₹5.95 cr for children with rare diseases: HC to state

EXPRESS NEWS SERVICE @Bengaluru

NOTING that it would be failing in its duties if it does not interfere when state and central governments have locked horns over funds to be spent on treatment of children suffering from a rare disease, 'Lysosomal Storage Disorder' (LSD), the Karnataka High Court directed the state government to release Rs 5.95 crore to treat 25 such children at Indira Gandhi Institute of Child Health in the city

In an interim order passed on Monday on public interest litigation filed by Lysosomal Storage Disorder Society of India, a division bench of Chief Justice Abhay Shreenivas Oka and Justice Hemant Chandangoudar said the state government has to release the amount in four monthly installments till June.

The bench cautioned that both state and central government will be responsible if any untoward incident happens due to failure in releasing the funds.

In a statement to the court, the IG-ICH Director said Rs 5.95 crore is re-

quired for treating the remaining 25 children for the next four months.

The bench asked the state government to submit a representation to the union government to release the funds for the treatment of children or to use the amount from the funds allotted for the health sector.

Notices

The bench also issued notices to the two companies, which supply drugs for LSDs, to get their response on supplying medicines at concessional prices or free

₹902 crore unspent

Meanwhile, the data submitted by the state indicated that ₹902 crore has remained unspent out of a total allocation of Rs 2,401 crore provided for the health sector for 2018-19. The government stated that it cannot reallocate the funds without the approval from the Ministry of Health and Family Welfare.

Interest is not sufficient

The bench pointed out that a corpus of Rs 17 crore was provided by the state to IGICH to treat LSD patients. But it is allowed to use only the interest amount for procuring drugs. As it requires Rs 40 lakh per year per child weighing about 10 kg, the cost of treatment increases by Rs 2 to 3 lakh for every extra one kg weight.



AWARENESS DRIVE

Racefor7: Rare disease patients, caregivers to hold multi-city march

CHENNAI: Patients suffering from rare diseases and their caregivers will participate in Racefor7, a multi-city run/walk to raise awareness for rare disease patients in India. The initiative aims to bring attention to the fact that it takes an average of seven years to diagnose a rare disease due to lack of awareness and diagnostics available. Besides, most treatments, even when available, is either not acces-

sible in India or beyond the reach of an average Indian patient, claimed health care experts here.

Patients and caregivers go through a very challenging time coupled with the lack of public access to patients who suffer from physical disabilities. Racefor7, symbolically representing 7,000 rare diseases and the average of seven years it takes to diagnose a rare disease, is first of its kind event for

rare diseases in the world with 7,000 people running/walking seven kilometres on February 29, marking World Rare Disease Day.

The run aims to draw attention towards the need for government support in creating a comprehensive Rare Diseases Policy for India as well as the

need of other stakeholders to create to a more supportive and inclusive environment for the rare disease community.

Dr Sujatha Jagadeesh, Geneticist and Metabolic Disorder specialist, Mediscan said, "Diagnosis of a metabolic disorder itself can take a long time and by then the patients would

have gone through an immense amount of suffering. Arriving at a precise diagnosis needs expertise and testing is expensive. After diagnosis, children would need modification in diet, continuous monitoring and expensive treatments by a multidisciplinary team. For this, the Government must support these Children. A public-private partnership model would be ideal to share the expertise and mobilize funds for the same."

Racefor7, symbolically representing 7,000 rare diseases, is first of its kind event for rare diseases in the world with 7,000 people participating in it

DT Next

ఆంధ్రజ్యోతి

తమిళ నాడు

శుక్రవారం

10

28 ఫిబ్రవరి

2020



ప్రెస్ క్లబ్ సమావేశంలో అవగాహన పత్రాలను చూపుతున్న ఓఆర్డీఐ సభ్యులు

అరుదైన వ్యాధుల నివారణ అవగాహనకై 1న 'రేస్ ఫర్ 7' పరుగు

చెన్నై, ఫిబ్రవరి 27 (ఆంధ్రజ్యోతి). ఓఆర్డీఐ ఆధ్వర్యంలో అరుదైన వ్యాధుల నివారణపై ప్రజల్లో అవగాహన కల్పించే లక్ష్యంతో మార్చి 1న నగరంలో రేస్ ఫర్ 7 కార్యక్రమం నిర్వహించనుంది. అదయార్ లోని ఆల్ఫాబ్ స్కూల్లో ఆ రోజు ఉదయం 6.30 గంటలకు పరుగు ప్రారంభమవుతుందని చెన్నై ప్రెస్ క్లబ్లో గురువారం ఏర్పాటుచేసిన మీడియా సమావేశంలో ఓఆర్డీఐ ప్రతినిధులు తెలిపారు. ఆ సందర్భంగా అరుదైన వ్యాధులతో బాధపడుతున్న రోగులు, వారి కుటుంబీకులు ఎదుర్కొంటున్న సవాళ్లను గురించి వివరించారు. మార్చి 29వ తేదీ వరకు

దశల వారీగా 20 నగరాల్లో అవగాహన పరుగు కార్యక్రమాలు నిర్వహించనున్నామని, 7వేల అరుదైన వ్యాధులకు గురైన ఈ కార్యక్రమానికి రేస్ ఫర్ 7 అనే పేరు పెట్టినట్లు ప్రతినిధులు పేర్కొన్నారు.

www.andhrajyothy.com



'రేస్ ఫర్ 7'కు విశేష స్పందన

కొరచుకోవటం ప్రమాణ స్వరూప సుస్థ అయిన అధికాక్షిపణ ధర్మ రేస్ డీజిజ్ (డబ్ల్యుడీఎ) ఆధ్వర్యంలో రేస్ ఫర్ 7 కిరీట అరుచిన వ్యాధుల ంస్థ అవగాహన మనోధాన్ అధికారం ఉదయం మనంగా జరిగింది. వెల్ఫేర్ ఆఫ్ డిఫెరింట్లీ మియల్లై వైజెల్లర్ వాసు లాన్స్ వర్గం, ఫీలత్ రేస్ కీరర్న ప్రాంతీయ వ్యవస్థాపక కేసీ జుంగ్ వైజెల్లర్ వాల్టర్ ఎన్ సురేష్ పాల్గొని రేస్ ఫర్ 7ను జిందా అపి ప్రారంభించారు. రెస్ట్రైట్ బొంబే మార్లో జరిగిన ఈ కార్యక్రమంలో అరుచిన వ్యాధిగ్రస్తలు, వైద్యులు, ఉద్యోగులు పెద్ద సంఖ్యలో పాల్గొన్నారు. మెడిసిన్స్ నిర్వహ్య వైజెల్లర్ వాల్టర్ సురేష్ జెనెటిక్ వాల్టర్ సుజాత జగదీష్ సీక్యూర్యం లో ఈ రేస్ జరిగింది.



రేస్ ఫర్ 7 పాల్గొన్న మానసిక వికారంగులు
విశేషంను పరచాలతో సక్య రిస్పన్స్ లభింపులు

వంద రేస్ డీజిజ్ డివీ ఉద్యమించుచును వన నిర్మించుచు అనే 77వ నిర్వహణ 350 మిలియన్ల మంది రేస్ డీజిజ్ ఏజెంట్లు అరుచిన వ్యాధులు, వ్యాధిగ్రస్తం వద్ద అవగా డిసట్ట వాసు వెల్లడించారు. ప్రపంచ వ్యాప్తంగా జనాభాని తెలిపారు.

Sakshi

ORDI Organizes Racefor7 to Raise Awareness and Advocacy for Rare Diseases

Chennai, February 28: The Organization for Rare Diseases India (ORDI), a not for profit organization committed to addressing the challenges of rare disease patients and their families, today announced the fifth edition of Racefor7, a multi-city run/walk to raise awareness for rare disease patients in India. Racefor7, symbolically representing 7000 rare diseases and the average of 7 years it takes to diagnose a rare disease, is a one of its kind event for rare diseases in the world with 7000 people running or walking 7 kilometers. The fifth edition will be on a much larger scale than before with events scheduled in 20 India cities. Racefor7 is held in February to commemorate World Rare Disease Day which falls on the last day of the month. This year's rare disease theme is Reframe Rare for Rare Disease Day with the message that 'Rare is many, rare is strong and rare is proud!' The campaign message reframes perceptions of what it means to be 'rare' so that no one is left behind in achieving greater equity.

- Facts about Rare Diseases:
- 350 million patients globally of which 70 million rare disease patients are in India
 - India has the world's third highest rare disease population, more than the whole population of Thailand
 - There are an estimated 7000 known rare diseases. Only 450 are recorded in India
 - Average of 7 years to diagnose a rare disease
 - Less than 5% of rare disease have available treatment, most unaffordable

A race to raise awareness about rare diseases

Children, wheelchair users take part

SPECIAL CORRESPONDENT CHENNAI
Scores of people, including children and wheelchair users, took part in a one-of-its-kind race to create awareness about rare diseases.

has grown into a campaign held across 20 cities in the country.

Need for policy
According to Prasanna Shirol, founder-director of Organisation for Rare Diseases India (ORDI) and father of a rare-disease patient, 50% of all rare disease patients are children. "We also need a supportive rare disease policy and institutions like corporates, schools and colleges to create a more inclusive environment for rare disease patients."
Dr. Suresh said that FCRF and Mediscan were working in the field of rare diseases for the past two decades and over 350 children had been provided treatment.

'Racefor7' was flagged off by Johnny Tom Varghese, director for the Welfare of the Differently Abled, and S. Suresh, founder and managing trustee of Fetal Care Research Foundation.
The participants ran 7 km, representing the 7,000 rare diseases.
February 28 is observed as World Rare Disease Day. The theme for Rare Disease Day this year is 'Reframe Rare for Rare Disease Day'. The message was 'Rare is many, rare is strong and rare is proud!'
Racefor7 began as an awareness walk in Bengaluru in February 2016, and



ORDI Organizes Racefor7 to Raise Awareness and Advocacy for Rare Diseases

Chennai, February 28, 2020: Need for comprehensive Rare Disease Policy says ORDI, Event to be held in 20 Indian cities

The Organization for Rare Diseases India (ORDI), a not for profit organization committed to addressing the challenges of rare disease patients and their families, today announced the fifth edition of Racefor7, a multi-city run/walk to raise awareness for rare disease patients in India. Racefor7, symbolically representing 7000 rare diseases and the average of 7 years it takes to diagnose a rare disease, is a one of its kind event for rare diseases in the world with 7000 people running or walking 7 kilometers. The fifth edition will be on a much larger scale than before with events scheduled in 20 India cities. Racefor7 is held in February to commemorate World Rare Disease Day which falls on the last day of the month. This year's rare disease theme is Reframe Rare for Rare Disease Day with the message that 'Rare is many, rare is strong and rare is proud!' The campaign message reframes perceptions of what it means to be 'rare,' so that no one is left behind in achieving greater equity.

"This year's Racefor7 comes soon after the release of the National Policy for Rare 2020 draft by the Government of India which the rare disease community has found wanting in several areas," said Prasanna

Shirol, Ashoka Fellow and Co-founder, ORDI, and the father of a rare disease patient. "We hope that this event will create an opportunity for more voices of the rare disease community to be heard across all stakeholders so that the rare disease community can lead a life of dignity and equality. We need to increase our efforts to show that 'rare isn't scarce, rare isn't infrequent, rare isn't remote' and the idea of holding Racefor7 in more cities this year is to show policy makers that rare is not as rare as it is made out to be." Collectively across the world, rare disease patients make up the third largest country in the world and in India, the rare disease community is about the size of Thailand's population.

It was in February, 2016, that ORDI organized the first Racefor7 in Bangalore to create awareness and a collective voice for the rare disease community. Since then, the event has grown in size and stature and is held in many cities across India and in select overseas countries. In 2020, Racefor7 will be held through February and March across 20 Indian cities - Ahmedabad, Bengaluru, Chennai, Coimbatore, Davanagere, Delhi, Hyderabad, Indore, Jaipur, Kochi, Kolkata, Mangaluru, Mumbai, Mysuru, Nagpur, Puducherry, Pune, Thiruvananthapuram, Vadodara and Vellore. Although an estimated 70 million patients in



India live with a rare disease, accessible and affordable treatment is still a long way away.

"IQVIA is delighted to be associated for the fifth consecutive year as the main sponsor of Racefor7 which is a unique way of bringing together rare disease patients, their caregivers and the community at large for a common cause. It is extremely rewarding to learn of the positive impact that Racefor7 has had for the rare disease community over the last five years," said Amit Mookim, Managing Director, IQVIA South Asia. Rare Diseases is a key therapeutic focus for IQVIA who has provided clinical services for more than 321 rare disease studies in 87 countries worldwide since 2014.

Dr Suresh, Director of Mediscan Systems and Managing Trustee of FCRFV says, "Fetal care Research Foundation & Mediscan have been working in the field of

Rare Diseases for the past 2 decades over 350 children have been provided Rare disease occurs infrequently in the population, which can be anything from 1 in 5000 to 1 in 100000. It is our moral responsibility to support these patients by creating awareness and join them in advocacy and help them to improve quality of life by bringing experts together under one roof.

DR Sujatha Jagadeesh, Geneticist and metabolic disorder specialist Mediscan says, "Diagnosis of a metabolic disorder itself can take a long time and by then the patients would have gone through immense amount of suffering. Arriving at a precise diagnosis needs expertise and testing is expensive. After diagnosis, the children would need modification in diet, continuous monitoring and expensive treatments by a multidisciplinary team.

HELLO MADRAS
EVERYDAY'S TRUTH UPDATED DAILY





Chennai Runs to Support Rare Disease Patients

Chennai, Mar 3; Racefor7, an initiative championed by the Organization for Rare Diseases India (ORDI), was organized in Chennai today to raise awareness for the rare disease community. [Thiru. Johny Tom Varghese, I.A.S., Director for the Welfare of Differently Abled and Dr. S. Suresh, Founder and Managing Trustee of Fetal Care Research Foundation (FCRF)] flagged-off the run and joined hundreds of people of Chennai, who participated in the run to show they Care for Rare. Racefor7, a first of its kind event for rare diseases in the world, symbolically represents 7000 rare diseases with 7000 people running for 7 kilometers to represent the average number of years it takes to diagnose a rare disease.

Although an estimated 1 in 20 Indians suffers from a rare disease, lack of awareness and information has created several challenges for patients and their caregivers, most importantly delayed diagnosis, affordable and targeted care and treatment and access. Besides members of the general public, several rare disease patients and their families participated in Racefor7 to draw attention to the challenges faced by rare disease patients, especially children, and the urgency for governments and other institutions to recognize their unique needs and create enabling policies and a more supportive environment for them.

Racefor7 is held in the month of February to commemorate World Rare Disease Day which falls on the last day of February. The theme for Rare Disease Day 2020 is 'Reframe Rare for Rare Disease Day' with the message that 'Rare is many, rare is strong and rare is proud!'. The campaign message reframes perceptions of what it means to be 'rare' so that no one is left behind in achieving greater equity. Racefor7, that started off as an awareness walk in Bangalore to commemorate World Rare Disease Day in February 2016, has now grown into a significant campaign that this year will be held across 20 Indian cities.

Prasanna Shirol, Founder Director, ORDI, and father of a rare disease patient, said, "50% of all rare disease patients are children. This is a fact not many are aware of and supports our urgency of spreading awareness about rare diseases so that early diagnosis and treatment can increase their life expectancy and quality of life. Besides lack of access to early intervention and treatment because of the lack of widespread awareness about rare diseases, the cost of treatment where available is often prohibitively expensive. We also need a supportive rare disease policy and institutions like corporates and schools and colleges to create a more inclusive environment for rare disease patients."



The Indian Express

Dainik Jagaran Kolkata



Race for rare diseases

Racefor7, an initiative championed by the Organization for Rare Diseases India (ORDI), was held recently to raise awareness for the rare disease community. Johnny Tom Varghese, director for the Welfare of Differently Abled and Dr S Suresh, founder and managing trustee of Fetal Care Research Foundation (FCRF) flagged-off the run. Racefor7, a first-of-its-kind event for rare diseases in the world, symbolically represents 7,000 rare diseases with 7,000 people running for 7 km to represent the average number of years it takes to diagnose a rare disease.

दुर्लभ बीमारियों से ग्रस्त बच्चों के समर्थन में दौड़ा महानगर

जागरण संवाददाता, कोलकाता : कोलकाता में रविवार को दुर्लभ बीमारी के मरीजों, जिनमें 50 प्रतिशत बच्चे हैं, के लिए ऑर्गनाइजेशन फॉर रेयर डिजीज इंडिया (ओआरडीआइ) की पहल पर 'रेस फर 7' का आयोजन किया गया। जानी-मानी हस्तियां ऊषा उथुप, अनिंद्य चटर्जी और रोमी दत्ता ने इस दौड़ को हरी झंडी दिखाई और दुर्लभ बीमारी के मरीजों के समर्थन में एकत्र हुए और दौड़ लगाने वाले कोलकातावासियों का साथ दिया। 'रेस फर 7' दुनिया भर में दुर्लभ बीमारी से जूझ रहे मरीजों के समर्थन में अपनी तरह का पहला आयोजन है।

इसमें 7000 तरह की दुर्लभ बीमारियों की संख्या को दर्शाने के लिए सांकेतिक रूप से 7000 लोगों ने दौड़ लगाई। इन बीमारियों का पता चलने में औसतन 7 साल का वक्त लग जाता है,



मौके पर दुर्लभ बीमारियों से ग्रस्त बच्चों के साथ गायिका उषा उथुप व अन्य। • जागरण

इसे सांकेतिक रूप से दर्शाने के लिए प्रतिभागियों ने 7 किलोमीटर की दौड़ लगाई। इस मौके पर ओआरडीआइ के संस्थापक निदेशक और दुर्लभ बीमारी से ग्रसित एक मरीज के पिता प्रसन्ना शिरोल, आइक्यूवीआइए के प्रबंध निदेशक

अमित मुकीम, मॉलीक्यूलर जेनेटिक्स में पीएचडी और ओआरडीआइ, पश्चिम बंगाल की जेनेटिक काउंसलर व को-ऑर्डिनेटर डॉ. दीर्घाजना दत्ता ने दुर्लभ बीमारी के मरीजों के प्रति जागरूकता फैलाने पर बल दिया।



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Mumbai runs to support rare disease patients

The-first-of-its-kind event for rare diseases in the world, Racefor7, represented 7,000 rare diseases with 7,000 people running for seven kilometers to represent the average number of years it takes to diagnose a rare disease

By **EH News Bureau** — On **Mar 2, 2020**

NEWS



The Indian Express



Organization for Rare Diseases will raise awareness on 7K-odd disorders | SAPTARSHI MUHERJEE

‘National policy on rare diseases is unscientific’

RANJANI MADHAVAN @Bengaluru

TERMING the draft national policy on rare diseases “unscientific”, the Organization for Rare Diseases India (ORDI) urged the Centre to make a budgetary allocation of Rs 400-600 crore for the treatment of such diseases and remove the Rs 15-lakh cap on the treatment cost.

In its list of 15 recommendations sent to the Ministry of Health and Family Welfare in response to the draft policy which the Union government came out on January 13 inviting inputs from the public, the Bengaluru-based not-for-profit sought disease-specific financial packages, waiver of GST and import duty on essential drugs and medical devices.

“The draft policy does not speak about the central government covering the treatment cost of rare diseases and only depends on crowd funding which is not sustainable when the treatment runs into crores each year per patient. The earlier draft included a cost sharing between the state and the centre in 40:60 ratio which has been removed from the new draft,” ORDI co-founder and executive director Prasanna Shirol said.

ORDI urged the ministry to create a rare diseases fund and share the cost of treatment with the state government in 60:40 ratio. There should be centres for treatments in every state and a national treatment centre, it recommended, adding that state and central tech-

nical committees should meet annually and take stock of rare diseases, drug price and therapies.

It also demanded a clear definition of rare diseases and called out the policy for its “unscientific and biased way of randomly selecting a few diseases to be covered.”

The organisation recommended putting orphan drug (intended for treatment of life threatening rare diseases) under price control. There must be a healthcare coverage for rare diseases, including recurring supportive treatment which is highly expensive, it advised.

“The lack of insurance coverage must change... It is unclear whether patients can avail assistance of multiple schemes such as Rashtriya Arogya Nidhi or Ayushman Bharat or both. There is no coverage for outpatient services, it said.

The organisation urged that the government encourage research and development for diseases which do not have any approved therapies.

“The policy must include pre-natal screening of high risk pregnancies and newborn screenings which can identify rare diseases in the first few days of baby’s life and result in life-saving changes,” the submission explained, also urging the government to create awareness among clinicians, supportive care personnel and make special medical foods and special wheelchair affordable and available to patients.

FOR A CAUSE

Kids, adults with rare diseases run to raise awareness

EXPRESS NEWS SERVICE
@Bengaluru

REFRAME RARE

Racefor7 is held in February to commemorate World Rare Disease Day. The theme for Rare Disease Day 2020 is ‘Reframe Rare for Rare Disease Day’ with the message that ‘Rare is many, rare is strong and rare is proud’. In Karnataka, the run will take place in Mysuru on March 8 and Davanagere on February 29.

ABOUT 150 children suffering from rare diseases took part in Racefor7, a multi-city run, to raise awareness on rare diseases. About 4,500-odd people took part in the run, which was flagged off by MP Tejasvi Surya, medical education minister Sudhakar and actor Shwetha Prasad.

Conducted by the Organization for Rare Diseases India (ORDI) and sponsored by IQVIA,

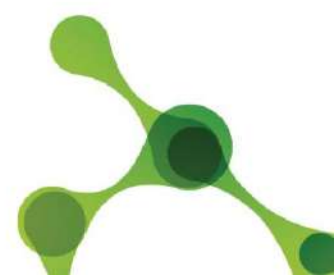
the run began from St Joseph’s Indian High School, near UB City. Racefor7 represents the 7,000-odd rare disease people suffer from, with people running for 7km to symbolise that it takes seven years on an average to diagnose a rare disease.

“They may be called rare but we cannot afford to ignore the 70 million rare disease patients in India. We all need to unite to create a more inclusive society for the rare disease community. Racefor7 has my complete support as do all the patients and

their families,” said MP Surya.

The lack of awareness among people and the lack of affordable treatment are hurdles. Prasanna Shirol, Founder Director, ORDI, and father of a rare disease patient, said, “About 50% of all rare disease patients are children. This is a fact not many are aware of.”

Dr Meenakshi Bhat, consultant, clinical genetics, Centre for Human Genetics, said, “In India, awareness about rare diseases is low among general public and doctors.”



Ee Naadu

Hosa Digantha

నల్ల నువ్వులను కలిపి నల్లని నువ్వులు ఏక అద్భుతం అవుతాయి.

అరుదైన వ్యాధులపై 23న జాగృతి జాతా

బెంగళూరు (మలేశ్యం), న్యూఢిల్లీ: అరుదైన వ్యాధులపై ప్రజల్లో జాగృతి కల్పించేందుకు రానున్న ఆదివారం నగరంలో రేస్ పర్-7 పేరిట జాతా నిర్వహిస్తామని వైద్యులు తెలిపారు. బుధవారం ఇక్కడ నిర్వహించిన సమావేశంలో వైద్యులు, వివిధ స్వచ్ఛంద సంస్థల ప్రతినిధులతో కలిసి ఐక్య విషయ దక్షిణ ఆసియా మేనేజింగ్ ప్రారంభిస్తామన్నారు. జాగృతికి సంబంధించిన గోడ డైరెక్టర్ ఆమిత్ మూకిమ్ విలేకరులతో మాట్లాడారు. ప్రతికలను ప్రతినిధులు ప్రదర్శించారు.



గోడ పత్రికను ప్రదర్శిస్తున్న వైద్యులు, స్వచ్ఛంద సంస్థల ప్రతినిధులు, వ్యాధి పీడితులు

దేశంలో సుమారు 7కోట్ల మంది అరుదైన వ్యాధులను కలిగి ఉన్నారని చెప్పారు. ప్రాణాంతకం కాకపోవడంతో కొన్ని అరుదైన వ్యాధుల గురించి జాగ్రత్తలు తీసుకునే వారి సంఖ్య తక్కువగా ఉండన్నారు. ఆ రోజు ఉదయం సెయింట్ జోసెఫ్ కళాశాల నుండి జాగృతి జాతాను ప్రారంభిస్తామన్నారు. జాగృతికి సంబంధించిన గోడ డైరెక్టర్ ఆమిత్ మూకిమ్ విలేకరులతో మాట్లాడారు. ప్రతికలను ప్రతినిధులు ప్రదర్శించారు.

జాగృతిగాని రేస్ ఫార్ 7

బెంగళూరు ఫి.19: భారతదాని అపరోపద కాయిలే సంస్థ (ఓఆర్ డిఐ) ఇదు లాభదాయక సంస్థయల్ల. ఆదరే అపరోపద కాయిలే ఎంబ సవాలిన సందర్భదల్లి రోగి మత్తు అవర కుటుంబదవరిగే బేంబలవారి నిల్లవ బద్ధతేయన్ను సంస్థే హేందిదే. హిగాగి ఐదనే ఆవృత్తియ రేస్ ఫార్ 7 ఎంబ బహు నగరగళ ఓటి / నడిగే ఆయోజిసవ మూలక భారతదల్లి అపరోపద కాయిలే కురితు జాగృతి మూడిసవ అభియాన ఫోజిసలూగత్తిదే. రేస్ ఫార్ 7 ఎంబదు 700 అపరోపద కాయిలేగళన్ను ప్రతినిధిసత్తదే. ఇష్టుమాత్తవల్ల ఈ కాయిలే ఇదే ఎంబు తిళియలు 7 వర్షగళు బేకె. హిగాగి ఈ కురితు జాగృతి మూడిసలు 7 కిలో మిటర్ దూరవన్ను 7000 జనరు ఓటి హాగూ నడిగే మూలక క్రమిసి జనజాగృతి మూడిసత్తిద్దారే. 5నే ఆవృత్తియ ఈ హిందిన ఆవృత్తిగింతలూ అతి దోడ్డదాగి ఆయోజిసలూగత్తిదే. హిగాగి భారతద 20

ప్రముఖ నగరగళల్లి ఆయోజిసలూగత్తిదే. రేస్ ఫార్ 7 ఎంబదు అపరోపద కాయిలే దిన ఎంబు ఫోజిసలూగిద్దు, ఇదన్ను తింగళ కేనేయ దిన ఆజరిసలూగత్తదే. ఈ వర్షద అపరోపద కాయిలేయ థిమ్ ఎందరే అపరోపద కాయిలే దినవన్ను అపరోపవారి మరుహేందిసవ్వుదు ఎందన్నలూగిదే. 'అపరోప హలవు, అపరోప సదృఢ, అపరోప హేమ్' ఎంబ సందేశవన్ను సారలూగత్తిదే. అపరోప ఎంబదు యారోబ్బరూ హేరగుళియలారదష్టు శ్రేష్ట సమానతే. 'అపరోపద కాయిలేగళ కురితు హలవు మార్గోపాయగళన్ను కండుకేళలు కేంద్ర సర్కారవు 2020ర నూతన రాష్ట్రీయ నితియన్ను ఫోజిసిద బేన్నల్లే ఈ వర్ష రేస్ ఫార్ 7 బందిదే' ఎంబు ఓఆర్ డిఐ సంస్థాపకరు, అపరోపద కాయిలే ఇరువవర తందేయాద ప్రసన్న శిరోళ, అశోక అవరు హేళిదరు.



Ee Sanje

Prajavani - Bangalore

ಫೆ.23ರಂದು ರೇಸ್ ಫಾರ್ 7 ಜಾಗೃತಿ ಕಾರ್ಯಕ್ರಮ

ಬೆಂಗಳೂರು, ಫೆ.19- ಅಪರೂಪದ ಕಾಯಿಲೆ ಕುರಿತು ರೇಸ್ ಫಾರ್ 7 ಎಂಬ ಜಾಗೃತಿ ಕಾರ್ಯಕ್ರಮವನ್ನು ಫೆ.23ರಂದು ಬೆಳಿಗ್ಗೆ 6.30ಕ್ಕೆ ನಗರದ ಸ್ಟೇಜ್ ಟೋರ್ಟ್ ಹೈಸ್ಕೂಲ್‌ನಲ್ಲಿ ಒಆರ್‌ಡಿಐ ಜೊತೆಗೂಡಿ ಎಂದು ಐಕ್ಯವಿಜ್ಞಾನ ದಕ್ಷಿಣ ವಿಜ್ಞಾನ ವ್ಯವಸ್ಥಾಪಕ ನಿರ್ದೇಶಕ ಅಮಿತ್ ಮೂಜೆವ್ ಹೇಳಿದರು.

ಸುದ್ದಿಗೋಷ್ಠಿಯಲ್ಲಿ ಮಾತನಾಡಿದ ಅವರು, ಜಾಗೃತಿ ಜಾಥಾವನ್ನು ಬೆಂಗಳೂರು, ಅಹಮದಾಬಾದ್, ಚೆನ್ನೈ, ಕೊಯಂಬತ್ತೂರು, ದಾವಣಗೆರೆ, ದೆಹಲಿ, ಹೈದರಾಬಾದ್, ಇಂದೋರ್, ಜೈಪುರ, ಕೊಚ್ಚಿ, ಕೋಲ್ಕತ್ತಾ, ಮಂಗಳೂರು, ಮುಂಬೈ ಮೈಸೂರು, ನಾಗಪುರ, ಪಾಂಡಿಚೇರಿ, ಪುಣೆ, ತಿರುವನಂತಪುರ, ವಡೋದರ ಹಾಗೂ ವೆಲ್ಲೂರಿನಲ್ಲಿ ಆಯೋಜಿಸಲಾಗಿದೆ ಎಂದರು.

ಭಾರತದಲ್ಲಿ ಅಂದಾಜು 7ಕೋಟಿ ಜನರು ಅಪರೂಪದ ಕಾಯಿಲೆಯಿಂದ ಬಳಲುತ್ತಿದ್ದು ಎಲ್ಲರಿಗೂ ಸರಿಯಾದ



ಚಿಕಿತ್ಸೆ ಹಾಗೂ ಕೈಗೊಳ್ಳುವ ದರದಲ್ಲಿ ಚಿಕಿತ್ಸೆ ಲಭ್ಯವಾಗುತ್ತಿಲ್ಲ ಹೀಗಾಗಿ ಇಂತಹ ರೋಗಿಗಳು ಸವಾಲಿನ ಗಳಿಗೆಯಲ್ಲಿ ಸಾಗುವಂತಾಗಿದೆ. ಹೀಗಾಗಿ ಜನರಲ್ಲಿ ಇದರ ಕುರಿತು ಜಾಗೃತಿ ಮೂಡಿಸಲು ರೇಸ್ ಫಾರ್ 7 ಕಾರ್ಯಕ್ರಮ ಆಯೋಜಿಸಲಾಗಿದೆ. ಆದ್ದರಿಂದ ಹೆಚ್ಚಿನ ಸಂಖ್ಯೆಯಲ್ಲಿ ಜನರು ಕಾರ್ಯಕ್ರಮದಲ್ಲಿ ಪಾಲ್ಗೊಂಡು ಅಪರೂಪ ಕಾಯಿಲೆ ಕುರಿತು ಸೂಕ್ತ ನೀತಿಯನ್ನು ಜಾರಿಗೊಳಿಸಲು ಸರ್ಕಾರಕ್ಕೆ ಒತ್ತಡ ಹೇರಬೇಕು ಎಂದರು. ರೋಗಿಗಳನ್ನು ಮತ್ತು ರೋಗಿಗಳ ಆರೈಕೆ ಮಾಡುವವರನ್ನು ಸೇರಿಸುವ ವಿನ್ಯಾಸವೇ ವೇದಿಕೆ ಕಲ್ಪಿಸಿ ಕಾಯಿಲೆ ಬಗ್ಗೆ ಸಕಾರಾತ್ಮಕವಾಗಿ ನೋಡಲು ಕಾರ್ಯಕ್ರಮ ನೆರವಾಗಿದೆ ಎಂದು ತಿಳಿಸಿದರು. ಅಪರೂಪದ ಕಾಯಿಲೆ ಇರುವ

ಅಪರೂಪದ ಕಾಯಿಲೆ ಜಾಗೃತಿ ನಡಿಗೆ



ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಕುರಿತು ಜಾಗೃತಿ ಮೂಡಿಸಲು ಭಾರತೀಯ ಅಪರೂಪದ ಕಾಯಿಲೆ ಸಂಸ್ಥೆ (ಓಆರ್‌ಡಿಐ) ಆಯೋಜಿಸಿರುವ 'ರೇಸ್ ಫಾರ್ 7' ನಡಿಗೆ ಮತ್ತು ಓಟದ ಪ್ರೋತ್ಸಾಹಗಳನ್ನು ಬುಧವಾರ ದಿಡುಗಡೆ ಮಾಡಿದ ಸಂಸ್ಥೆಯ ಸದಸ್ಯರು ಮತ್ತು ಕಾರ್ಯದರ್ಶಿಗಳು.

- ಮೂರನೇ ಸ್ಥಾನದಲ್ಲಿ ಭಾರತ
- ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಪಟ್ಟಿಯಲ್ಲಿ ಭಾರತಕ್ಕೆ ಮೂರನೇ ಸ್ಥಾನ
 - ಭಾರತದಲ್ಲಿ ಬಹು ಕೋಟಿ ಜನರು ಈ ಕಾಯಿಲೆಯಿಂದ ಬಳಲುತ್ತಿದ್ದಾರೆ. ಇದು ಥಾಯ್‌ಲ್ಡ್ ಜನಸಂಖ್ಯೆಗೆ ಸಮ
 - ಈ ಕಾಯಿಲೆ ಪತ್ತೆಯಾಗಲು ಕನಿಷ್ಠ ಏಳು ವರ್ಷ ಬೇಕು
 - ಈ ಕಾಯಿಲೆಗಳು ಬಹುತೇಕ ಅನುವಂಶಿಕ
 - ಬಹಳಷ್ಟು ಕಾಯಿಲೆಗಳಿಗೆ ಭಾರತದಲ್ಲಿ ಚಿಕಿತ್ಸೆ ಲಭ್ಯ ಇಲ್ಲ. ಇರುವ ಚಿಕಿತ್ಸೆಯೂ ಭಾರಿ ಬಡಬಾರಿ

ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಕುರಿತು ಜಾಗೃತಿ ಮೂಡಿಸಲು ಭಾರತೀಯ ಅಪರೂಪದ ಕಾಯಿಲೆ ಸಂಸ್ಥೆ (ಓಆರ್‌ಡಿಐ) 'ರೇಸ್ ಫಾರ್ 7' ನಡಿಗೆ ಮತ್ತು ಓಟ ಆಯೋಜಿಸಿದೆ. 'ರೇಸ್ ಫಾರ್ 7' ಅಧಿಯಾನದ ಏಳು ಸಂಖ್ಯೆ ಏಳು ಸಾವಿರ ಅಪರೂಪದ ಕಾಯಿಲೆಗಳನ್ನು ಪ್ರತಿನಿಧಿಸುತ್ತದೆ. ಈ ಕಾಯಿಲೆಗಳು ಗೋಚರಿಸಲು ಕನಿಷ್ಠ ಏಳು ವರ್ಷ ಬೇಕಾಗುತ್ತದೆ. ಜಾಗೃತಿ ನಡಿಗೆ ಮತ್ತು ಓಟದಲ್ಲಿ ಏಳು ಕಿಮೀಟರ್ ದೂರವನ್ನು ಏಳು ಸಾವಿರ ಜನರು ಕ್ರಮಿಸುತ್ತಾರೆ. ಐದನೇ ಅವಧಿ ಜಾಗೃತಿ ನಡಿಗೆ ಫೆಬ್ರವರಿ 23ರಂದು ಬೆಳಿಗ್ಗೆ 6.30ಕ್ಕೆ ಯು.ಪಿ. ಓಟ ಎದುರಿನ ಸ್ಟೇಜ್ ಟೋರ್ಟ್ ಇಂಡಿಯನ್ ಹೈಸ್ಕೂಲ್ ಮೈದಾನದಿಂದ ಆರಂಭವಾಗಲಿದೆ. ಫೆಬ್ರವರಿ ಕೊನೆಯ ವಾರ 'ರೇಸ್ ಫಾರ್ 7' ಅಪರೂಪದ ಕಾಯಿಲೆ ದಿನ ಎಂದು ಆಚರಿಸಲಾಗುತ್ತದೆ. 'ಅಪರೂಪದ ಕಾಯಿಲೆಯನ್ನು ಅಪರೂಪವಾಗಿ ಮರು ಹೊಂದಿಸುವುದು' ಈ ವರ್ಷದ ಧ್ಯೇಯ ವಾಕ್ಯ ಮತ್ತು 'ಅಪರೂಪ ಹಲವು. ಅಪರೂಪ ಸದೃಶ ಮತ್ತು ಅಪರೂಪ ಹೆಮ್ಮೆ' ಎಂಬ ಸಂದೇಶ ಸಾರಲಾಗುತ್ತಿದೆ. ಬೆಂಗಳೂರು ಸೇರಿದಂತೆ ರಾಜ್ಯದ ದಾವಣಗೆರೆ (ಫೆ.29) ಮತ್ತು ಮೈಸೂರು (ಮಾರ್ಚ್ 8) ಮತ್ತು ಫೆಬ್ರುವರಿ/ ಮಾರ್ಚ್‌ನಲ್ಲಿ ದೇಶದ 20 ನಗರಗಳಲ್ಲಿ 'ರೇಸ್ ಫಾರ್ 7' ಜಾಗೃತಿ ನಡಿಗೆ ಆಯೋಜಿಸಲಾಗಿದೆ. ಇಂಥ ಕಾಯಿಲೆಯಿಂದ ಬಳಲುತ್ತಿರುವ ಮಕ್ಕಳು, ಮಹಿಳೆಯರು, ರೋಗಿಗಳು ಮತ್ತು ಅವರ ಕುಟುಂಬ ಸದಸ್ಯರು ಸುದ್ದಿಗೋಷ್ಠಿಯಲ್ಲಿ ಹಮ್ಮಿ ಅನುಭವ ಹಂಚಿಕೊಂಡರು. ಜಾಗೃತಿ ನಡಿಗೆ ಮತ್ತು ಓಟದಲ್ಲಿ ಪಾಲ್ಗೊಳ್ಳಲು ಬಯಸುವ ಆಸಕ್ತರು <http://registration.racefor7.com/> ಇಲ್ಲಿ ಹೆಸರು ನೋಂದಣಿ ಮಾಡಿಸಿಕೊಳ್ಳಬಹುದು.

ಮೈದಾನದಿಂದ ಆರಂಭವಾಗಲಿದೆ. ಫೆಬ್ರವರಿ ಕೊನೆಯ ವಾರ 'ರೇಸ್ ಫಾರ್ 7' ಅಪರೂಪದ ಕಾಯಿಲೆ ದಿನ ಎಂದು ಆಚರಿಸಲಾಗುತ್ತದೆ. 'ಅಪರೂಪದ ಕಾಯಿಲೆಯನ್ನು ಅಪರೂಪವಾಗಿ ಮರು ಹೊಂದಿಸುವುದು' ಈ ವರ್ಷದ ಧ್ಯೇಯ ವಾಕ್ಯ ಮತ್ತು 'ಅಪರೂಪ ಹಲವು. ಅಪರೂಪ ಸದೃಶ ಮತ್ತು ಅಪರೂಪ ಹೆಮ್ಮೆ' ಎಂಬ ಸಂದೇಶ ಸಾರಲಾಗುತ್ತಿದೆ. ಬೆಂಗಳೂರು ಸೇರಿದಂತೆ ರಾಜ್ಯದ ದಾವಣಗೆರೆ (ಫೆ.29) ಮತ್ತು ಮೈಸೂರು (ಮಾರ್ಚ್ 8) ಮತ್ತು ಫೆಬ್ರುವರಿ/ ಮಾರ್ಚ್‌ನಲ್ಲಿ ದೇಶದ 20 ನಗರಗಳಲ್ಲಿ 'ರೇಸ್ ಫಾರ್ 7' ಜಾಗೃತಿ ನಡಿಗೆ ಆಯೋಜಿಸಲಾಗಿದೆ. ಇಂಥ ಕಾಯಿಲೆಯಿಂದ ಬಳಲುತ್ತಿರುವ ಮಕ್ಕಳು, ಮಹಿಳೆಯರು, ರೋಗಿಗಳು ಮತ್ತು ಅವರ ಕುಟುಂಬ ಸದಸ್ಯರು ಸುದ್ದಿಗೋಷ್ಠಿಯಲ್ಲಿ ಹಮ್ಮಿ ಅನುಭವ ಹಂಚಿಕೊಂಡರು. ಜಾಗೃತಿ ನಡಿಗೆ ಮತ್ತು ಓಟದಲ್ಲಿ ಪಾಲ್ಗೊಳ್ಳಲು ಬಯಸುವ ಆಸಕ್ತರು <http://registration.racefor7.com/> ಇಲ್ಲಿ ಹೆಸರು ನೋಂದಣಿ ಮಾಡಿಸಿಕೊಳ್ಳಬಹುದು.

ರೇಸ್ ಫಾರ್ 7

'ಅಪರೂಪ ಎಂದರೆ ಭಯ ಬೀಳಬೇಕಿಲ್ಲ'

'ಅಪರೂಪ ಎನ್ನುವುದು ಯಾವಾಗಲೋ ಅಲ್ಲ, ಅದು ದೂರದಲ್ಲಿ ಇಲ್ಲ ಮತ್ತು ಅದು ಅಂದುಕೊಂಡಷ್ಟು ತೀರಾ ಅಪರೂಪವಲ್ಲ. ಅದು ಭಯವೂ ಅಲ್ಲ ಎಂದು ಜನರಿಗೆ ತಿಳಿಸುವ ಪ್ರಯತ್ನವೇ ಜಾಗೃತಿ ನಡಿಗೆ ಮತ್ತು ಓಟ' ಎಂದು ಓಆರ್‌ಡಿಐ ಸಹ ಸಂಸ್ಥಾಪಕ ಪ್ರಸನ್ನ ಶಿರೋಳ ಬುಧವಾರ ಸುದ್ದಿಗೋಷ್ಠಿಯಲ್ಲಿ ತಿಳಿಸಿದರು.

ಅಪರೂಪದ ಕಾಯಿಲೆಗಳ ಬಗ್ಗೆ ತಿಳಿಯಲು ಮತ್ತು ಇಂಥ ರೋಗಿಗಳಿಗೆ ಸಕಾರಾತ್ಮಕವಾಗಿ ಸ್ಪಂದಿಸಲು ಜಾಗೃತಿ ಕಾರ್ಯಕ್ರಮ ನೆರವಾಗಲಿದೆ. ಕೆಲವು ವರ್ಷಗಳಿಂದ ನಡೆಯುತ್ತಿರುವ ಕಾರ್ಯಕ್ರಮಕ್ಕೆ ಸಕಾರಾತ್ಮಕ ಪ್ರತಿಕ್ರಿಯೆ ದೊರೆಯುತ್ತಿದೆ. ರೋಗಕ್ಕೆ ಚಿಕಿತ್ಸೆ ಇಲ್ಲದ ಕಾರಣ ಸಕಾರಾತ್ಮಕ ನಿರ್ವಹಣೆಯಿಂದೇ ಸದ್ದದ ಮಾರ್ಗ ಎಂದು ಡಾ. ಮೀನಾಕ್ಷಿ ಭಟ್ ಹೇಳಿದರು.

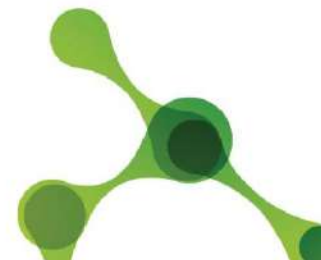
ದೇಶದ ಪ್ರತಿ ಐವರಲ್ಲಿ ಒಬ್ಬರು ಇಂಥ ಕಾಯಿಲೆಗಳಿಗೆ ತುತ್ತಾಗುತ್ತಿದ್ದಾರೆ. ಇಂಥ ರೋಗಿ ಭಾವಿಸುತ್ತಿದೆ ಎಂದು ಅರಿವಿಗೆ ಬರುವುದರೊಳಗೆ ಹಲವು ವರ್ಷ ಉರುಳಿ ಹೋಗುತ್ತವೆ ಎಂದು ಡಾ. ಅನಿತಾ ತಿಳಿಸಿದರು. ರೋಗ ಪತ್ತೆ ಕಷ್ಟ ಚಿಕಿತ್ಸೆ ಬಹಳ ದುಬಾರಿ. ಬಹುತೇಕ ಅಪರೂಪದ ರೋಗಿಗಳಿಗೆ ನಿರ್ದಿಷ್ಟ ಚಿಕಿತ್ಸೆ ಇಲ್ಲದಿರುವುದೇ ಸಮಸ್ಯೆ ದಿಗ್ಗಜಾಯಿಸಲು ಕಾರಣ ಎಂದು ತಿಳಿಸಿದರು.

ಶ್ರೀಂಗಿತ ಸಹಾಯ

ನನ್ನ ಆಯುರ್ವೇದಿಕ ಔಷಧವನ್ನು ಉಪಯೋಗ ಮಾಡಿ ಸೆಲ್ ಸಹಾಯ

ಬಹುದಾದಂತೆ ಪಟ್ಟಣಕ್ಕೂ ಹಾಗೂ ಲಿಂಗ ಪರ್ಯಟನೆಯ ನಿಮ್ಮ ಲಿಂಗದ ಗಾತ್ರವನ್ನು ಪಟ್ಟಣಕ್ಕೂ ಕರೆ-800,1200

ಉಪಯುಕ್ತ ಸಂಖ್ಯೆ 08317718207



Hosa Digantha – Bangalore

Sandesh City - Ahmedabad

ರೇಸ್‌ಫಾರ್‌7 ಜಾಗೃತಿ ಕಾರ್ಯಕ್ರಮ

ಬೆಂಗಳೂರು: ಅಪರೂಪದ ಕಾಯಿಲೆ ಕುರಿತು ಜನರಲ್ಲಿ ಜಾಗೃತಿ ಮೂಡಿಸುವ ನಿಟ್ಟಿನಲ್ಲಿ ರೇಸ್‌ಫಾರ್‌7 ಜಾಗೃತಿ ಕಾರ್ಯಕ್ರಮ ಫೆ.23ರಂದು ಬೆಂಗಳೂರಿನ ಸೈಂಟ್ ಜೋಸೆಫ್ ಹೈಸ್ಕೂಲ್ ನಲ್ಲಿ ಒಆರ್‌ಡಿಐ ಆಯೋಜಿಸಿದೆ ಎಂದು ಐಕ್ಯೋವಿಐಎ ದಕ್ಷಿಣ ಏಷ್ಯಾದ ವ್ಯವಸ್ಥಾಪಕ ನಿರ್ದೇಶಕ ಅಮಿತ್ ಮೂಕಿಮ್ ಹೇಳಿದರು.

ಸುದ್ದಿಗೋಷ್ಠಿಯಲ್ಲಿ ಮಾತನಾಡಿದ ಅವರು, ರೇಸ್‌ಫಾರ್‌7 ಜಾಗೃತಿ ಕಾರ್ಯಕ್ರಮ ದೇಶದ ಪ್ರಮುಖ ನಗರಗಳಾದ ಬೆಂಗಳೂರು, ದಾವಣಗೆರೆ, ಅಹಮದಾಬಾದ್, ಚೆನ್ನೈ, ಕೊಯಂಬತ್ತೂರು, ದಾವಣಗೆರೆ, ದೆಹಲಿ, ಹೈದರಾಬಾದ್, ಇಂದೋರ್, ಜೈಪುರ, ಕೊಚ್ಚಿ, ಕೋಲ್ಕತ್ತಾ, ಮಂಗಳೂರು, ಮುಂಬೈ, ಮೈಸೂರು, ನಾಗಪುರ ಸೇರಿದಂತೆ ಒಟ್ಟು 20ನಗರಗಳಲ್ಲಿ ನಡೆಯಲಿದೆ ಎಂದರು.

ದೇಶದಲ್ಲಿ ಸುಮಾರು 2ಕೋಟಿ ಜನರು ಅಪರೂಪದ ಕಾಯಿಲೆಯಿಂದ ಬಳಲುತ್ತಿದ್ದು, ಎಲ್ಲರಿಗೂ ಸರಿಯಾದ ಹಾಗೂ ಕೈಗೆಟುಕುವ ದರದಲ್ಲಿ ಚಿಕಿತ್ಸೆ ಸಿಗುತ್ತಿಲ್ಲ. ಇದರಿಂದಾಗಿ ರೋಗಿಗಳು ಸವಾಲಿನ ಗಳಿಗೆಯಲ್ಲಿ ಸಾಗುವಂತಾಗಿದೆ. ಹೀಗಾಗಿ ಜನರಲ್ಲಿ ಇದರ ಕುರಿತು ಜಾಗೃತಿ ಮೂಡಿಸಲು ರೇಸ್‌ಫಾರ್‌7 ಎಂಬ ಕಾರ್ಯಕ್ರಮ ಆಯೋಜಿಸಲಾಗಿದೆ. ಹೆಚ್ಚಿನ ಸಂಖ್ಯೆಯಲ್ಲಿ ಜನರು ಪಾಲ್ಗೊಂಡು

ರೇಸ್‌ಫಾರ್‌7 ಎಂಬುದು 7000ರೀತಿಯ ಅಪರೂಪದ ಕಾಯಿಲೆಯಾಗಿದೆ. ಹೀಗಾಗಿ ಇದರ ಕುರಿತು ಜಾಗೃತಿ ಮೂಡಿಸುವ ನಿಟ್ಟಿನಲ್ಲಿ 7ಕಿ.ಮೀ. ದೂರವನ್ನು 7ಸಾವಿರ ಜನರು ಓಟ ಹಾಗೂ ನಡಿಗೆ ಮೂಲಕ ಕ್ರಮಿಸಿ ಜನಜಾಗೃತಿ ಮೂಡಿಸಲಾಗುತ್ತಿದೆ.

ಅಮಿತ್ ಮೂಕಿಮ್, ಐಕ್ಯೋವಿಐಎ ದಕ್ಷಿಣ ಏಷ್ಯಾದ ವ್ಯವಸ್ಥಾಪಕ ನಿರ್ದೇಶಕ

ಅಪರೂಪದ ಕಾಯಿಲೆ ಬಗ್ಗೆ ಸೂಕ್ತ ನೀತಿ ಜಾರಿಗೊಳಿಸಲು ಸರ್ಕಾರಕ್ಕೆ ಒತ್ತಡ ಹೇರಬೇಕು ಎಂದರು.

ಅಪರೂಪದ ಕಾಯಿಲೆ ಇರುವ ರೋಗಿಯ ತಂದೆ ಪ್ರಸನ್ನ ಶಿರೋಳ ಮಾತನಾಡಿ, ಕೇಂದ್ರ ಸರ್ಕಾರ 2020ರ ನೂತನ ರಾಷ್ಟ್ರೀಯ ನೀತಿ ಘೋಷಿಸಿದ ಬೆನ್ನಲ್ಲೆ ರೇಸ್‌ಫಾರ್‌7 ಬಂದಿದ್ದು, ಈ ಕಾರ್ಯಕ್ರಮದಿಂದ ಸಕಾರಾತ್ಮಕ ಪ್ರಕ್ರಿಯೆ ಲಭಿಸಲಿದೆ. ಈ ಹಿಂದೆ ಕಾಯಿಲೆ ಕುರಿತು ಜಾಗೃತಿ ಮೂಡಿಸಲಾಗಿದೆ. ಆದರೆ ಇದರ ಕುರಿತಾದ ಜಾಗೃತಿ ಇನ್ನಷ್ಟಾಗಬೇಕು ಎಂದರು.

असाधारण रोगो प्रत्ये जागृति लाववा अनोपनी गोन कोम्पिटेटिव रेसगुं आयोजन करायुं



असाधारण रोगींनी जागृति माटे तेमज परिवारना आ रोगी सामेना पसकारी प्रत्ये जागृति लाववा माटे ऑर्गेनाइजेशन कोर रेड डिस्सीज रनिश्या द्वारा अनोपनी गोन कोम्पिटेटिव रेसकोस ओ योजवामां आनी उती. प्रतिक्रामक रीते रेसकोस ओ द्वारा ७,००० असाधारण रोगी सामे आल्या छे जे वल्ली मोटी वात कडेवाय. तेथी ऑर्गेनाइजेशन कोर रेड डिस्सीज द्वारा लोकामां तेने वरुने जागृतना हेलाववा माटे भारतामां २० शतकेमां मार्चमां रेस योजवानी छे. आ कम्पेर्शनमां ७,००० लोक जेसया छे,जेओ

अक साथे दिसयां अने ७ किलोमीटर वोक कर्तुं. अमदावादांमां पत्र रविवारे आ मेरेथोन योजर. जागृतिनी अभाव अने डायग्नोस्टिकसना अभावने कारणे कोर असाधारण रोगगुं निदान करवामां सरैराश सात वर्ष लागीं जाय छे ते उपरांत, उपलब्ध छीय त्यारे मोटाभागनी सारवार त्यां ती भारतामां सुलभ छीती नथी अथवा सरैराश भारतीय दडीनी पळोयथी भडार छीय छे. तेथी ते अंगे जागृति लाववा अक वोकगुं आयोजन डिडेवलीन पाते करवामां आयुं छुं.



Sakaal Times

Rare marathon to be held in city tomorrow

ST CORRESPONDENT
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PUNE: A rare marathon will be held in the city on Sunday where children, adults, families and friends of patients suffering from rare diseases will participate. The 'Race for 7' will be held on February 16 at The Queen Mary Technical Institute for Differently Abled Soldiers at Range Hills.

Such races are organised across India to spread awareness about the issue of rare diseases by Organization for Rare Disease India, a Bengaluru-based NGO, in line with World Rare Diseases Day celebrated on February 29.

The aim is to raise awareness about rare diseases, to bring together a wide range of stakeholders, to raise aware-

ness and to sensitise the society about rare diseases. The race also focuses on to empower patients and their families with access to resources for continued treatment and to fuel advocacy efforts at state and national level in devising the right policies in the interest of patients.

Nivedita, a rare disease patient suffering from Duchenne Muscular Dystrophy (DMD), is also a part of this initiative. DMD is a severe type of muscular dystrophy and the symptom of muscle weakness usually begins around the early age.

"I urge patients and families to come and attend the race as it is a platform for all stakeholders to know each other and help each other," said Nivedita.

CITY FIRST

A non-competitive run was organized by the Organization for Rare Diseases India (ORDI) as part of its 'Racefor7' initiative in Ahmedabad on Sunday. Hundreds of runners participated in this run, that ended at Decathlon, Applewoods.

The event was aimed at creating awareness about the challenges faced by rare disease patients and their families. The initiative 'Racefor7' represents 7,000 rare diseases with 7,000 people running or walking seven kilometres. Started in February, it has covered 20 cities in the country - Ahmedabad, Bengaluru, Chennai, Coimbatore, Davanagere, Delhi, Hyderabad, Indore, Jaipur, Kochi, Kolkata, Mangaluru, Mumbai, Mysuru, Nagpur, Puducherry, Pune, Thiruvananthapuram, Vadodara and Vellore.



FOR THE GIFT OF LIFE



रेयर डिजीज के प्रति जागरूकता फैलाने दौड़ेंगे शहरवासी

इंदौर। प्रत्येक वर्ष फरवरी के अंतिम दिन रेयर डिजीज डे मनाया जाता है। इस डे को मनाने का उद्देश्य आम लोगों को दुर्लभ किस्म के रोगों की जानकारी देना और उनके प्रति जागरूकता फैलाना है। ऑर्गेनाइजेशन फॉर रेयर डिजीज इंडिया द्वारा लियो लीजेंड्स, रोटरी प्रोफेशनल्स, टैबलर्स, साइक्लो फ्रिक्स, अकादमी ऑफ इंदौर मैराथनर्स और लियो के सहयोग से यह वॉक 'रेस फॉर सेवन' के नाम से 15 मार्च को आयोजित की जा रही है।

वॉक को इंदौर लेकर आई सुरभि मनोचा चौधरी जो स्वयं एक रेयर डिजीज वारियर हैं, ने बताया कि अब तक करीब 7 हजार किस्म की दुर्लभ बीमारियों के बारे में पता चला है, इसलिए यह वॉक 7000 मीटर की होगी, जो विजय नगर से शुरू होगी। उन्होंने बताया कि यह वॉक देश के 20 प्रमुख शहरों में कराई जा रही है। वॉक में शामिल होने के लिए रेयर डिजीज पेशेंट्स और स्पेशलीएबल्ड के लिए रजिस्ट्रेशन निःशुल्क है। वॉक के पहले जिन कृतिका वार्मअप करवाएंगी। कोर कमेटी में नीलेश अग्रवाल, अनुराग बोथरा, अनुभव दुबे, डॉ. श्रुति मारु, मनीष लुल्ला, चंद्रेश जुरानी, डॉ. प्रियंका तिवारी, वर्षा बिदासरिया, संजय टुटेजा, रचित पाटनी, नितिन चतुर्वेदी आदि शामिल हैं।

दैनिक भास्कर

29-Feb-2020

इंदौर सिटी भास्कर Page 5

रेयर डिजीज के लिए अवेयरनेस रन 15 मार्च को, रन का पोस्टर रिलीज किया

सिटी रिपोर्टर . इंदौर

ऑर्गेनाइजेशन फॉर रेयर डिजीज इंडिया देश के 20 शहरों में रेस फॉर सेवन वॉक और रन करा रहा है। इस फरवरी को आखिरी दिन मनाया जाता है। इंदौर में इसकी अवेयरनेस के लिए 15 मार्च को अवेयरनेस रन एक गार्डन से शुरू होगी। यह सात किलोमीटर की रन और वॉक है। यह रेयर डिजीज पेशेंट्स और स्पेशली-एबल्ड के लिए निःशुल्क होगी। रन शुरू होने के पहले कृतिका वॉर्म उप करवाएंगी। रन में टी-शर्ट, बिब और स्नैक्स रजिस्ट्रेशन में शामिल हैं। इसकी स्ट्रेटजी बनाने में अकडेमी ऑफ इंदौर मैराथनर्स ने मदद की है। कई संस्थान और शहर के



विशेष व्यक्ति इस से जुड़े है। इस रन को सुरभि मनोचा चौधरी ऑर्गेनाइज कर रही हैं। इसकी कोर कमेटी में कमेटी अक्षय कांति बम, नीलेश अग्रवाल, अनुराग बोथरा, अनुभव दुबे, डॉ. श्रुति मारु, मनीष लुल्ला, चंद्रेश जुरानी, डॉ. प्रियंका

तिवारी, वर्षा बिदासरिया, संजय टुटेजा, रचित पाटनी, नितिन चतुर्वेदी शामिल हैं। इस रन का पोस्टर भी रिलीज किया गया। इसमें लियो लेजेंड्स, रोटरी प्रोफेशनल्स टैबलर्स, साइक्लो फ्रीक्स, लियो, ओल्ड स्पान जैसी संस्थाएं जुड़ी हैं।

क्ष, को कि रखे की पृष्ठ बहु बहु यह स्प दिर सा थे, मुई हैं। करें मद ये : के





2/18



Dr Tangu, programme organiser said that after a gap of eight years, the bird count is being held in Mysuru and the gathered information will be helpful to keep a track of the bird species.

"Birds are indicators of our environment. If we have a good environment, nature, water bodies, the numbers of birds will be on the rise. The sad part

compared.

S Shylajesh, an avid bird watcher and member of Mysore Nature, who was part of the bird count said: "I was very disappointed about the death of Northern Shoveler birds reported at Lingambudhi Lake in November 2019. Today, I felt extremely happy spotting more than 600 Northern Shoveler birds in the lake. By main-

Run to raise awareness about rare diseases

EXPRESS NEWS SERVICE @Mysuru

'RACE FOR 7', a multi-city run/walk to raise awareness for rare disease patients in India has been organised by Organisation for Rare Diseases India (ORDI), a not-for-profit organisation committed to addressing the challenges of rare disease patients and their families.

The second edition of the 'Race for 7' will be held on March 8 from Balarama gate with 1,000 people running or walking 7 kilometre. The run will symbolically represent 7,000 rare diseases and an average of 7 years that takes to diagnose a rare disease.

Addressing media persons here on Friday, Prasanna Shi-

rol, co-founder and executive director, ORDI said through 'Race for 7', they aim to spread awareness about challenges faced by rare disease patients in India and the urgent need of providing resources and care to treat them.

"One in every 20 Indians suffer from a rare disease which is serious and life-threatening. There are 7,000 identified rare diseases with an estimated seven crore people in India affected with one or the other disease. Most of the rare disease patients are children. Thus, through the run we are creating awareness among people and are extending support to affected people," added Prasanna, father of a rare disease patient.

અસાધારણ રોગો પ્રત્યે જાગૃતિ લાવવા ઓર્ગનાઇઝેશન ફોર રેર ડિઝીઝ ઈન્ડિયા દ્વારા અમદાવાદમાં 'રેસફોર્સ ૭' યોજાશે

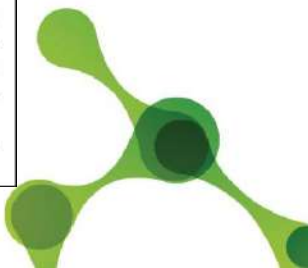
રેસફોર્સ ૭ ભારતના જુદા જુદા ૨૦ શહેરોમાં આયોજીત કરાઈ અમદાવાદ, તા.૧ જે રેકાથલોન, અપલવુડ્સ, એસ.જી.હાઈવે પર શરૂ થશે.

ઓર્ગનાઇઝેશન ફોર રેર ડિઝીઝ ઈન્ડિયા દ્વારા દેશભરમાં અનોખી નોન કોમ્પિટેટીવ રન 'રેસફોર્સ ૭' યોજવામાં આવે છે. અસાધારણ થતા રોગોની જાગૃતિ માટે તેમજ પરિવારના આ રોગો સામેના પડકારો પ્રત્યે જાગૃતિ લાવવા માટે આ પ્રોગ્રામ આયોજીત કરાય છે. પ્રતિકાત્મક રીતે રેસફોર્સ ૭ દ્વારા ૭,૦૦૦ અસાધારણ રોગો સામે આવ્યા છે જે ઘણી મોટી વાત કહેવાય જેના કારણે અનેક લોકોમાં જાગૃતતા લાવવાના કાર્ય ઓરડીઆઈ દ્વારા કરાયું છે.

જેથી આ કેમ્પેઈનને આગળ વધારવા માટે ૨૦૨૦ સુધીમાં 'રેસફોર્સ ૭' ભારતના ૨૦ શહેરોમાં યોજાઈ રહી છે જેની શરૂઆત ૭ ફેબ્રુઆરીથી થઈ ગઈ જે માર્ચ મહિના સુધી ચાલશે. આ કેમ્પેઈનમાં અત્યાર સુધી ૭,૦૦૦ લોકો જોડાયા છે જેઓ એક સાથે દોડ્યા હોય જે માટે ૭ કિલોમિટરની વોક યોજાય છે. આ કેમ્પેઈન અમદાવાદ, બેંગલુરુ, ચેન્નાઈ, કોઈમ્બતુર, દવાનાગર, દિલ્લી, હેદરાબાદ, ઈન્દોર, જયપુર, કોચી, કોલકાતા, મેંગલુરુ સુંબઈ, મૈસુરુ, નાગપુર, પુડુચેરી, પુણે તેમજ તિરુવનંતપુરમ, વડોદરા અને વેલોરમાં યોજાશે. ગુજરાત ખાતે અમદાવાદમાં 'રેસફોર્સ ૭' તારીખ ૧ માર્ચના રોજ વહેલી સવારે ૬:૩૦ વાગ્યે યોજાશે. આ દોડમાં સેંકડો દોડવીરોની ભાગ લેવાની અપેક્ષા છે

જેમાંની કેટલીક બિમારીઓ એવી છે કે જેના વિશે ડોકટરો પણ ઓછું જાણતા હોય છે અથવા જાણતા પણ નથી. આ જાગૃતિ દોડનો ઉદ્દેશ્ય એ છે કે સરકાર આ તરફ ધ્યાન આપે. આ અસાધારણ બીમારીઓનો સામનો કરી રહેલા બાળકોએ સાવચેતી રાખવી. જાગૃતિનો અભાવ અને ડાયગ્નોસ્ટિક્સના અભાવને કારણે કોઈ અસાધારણ રોગોનું નિદાન કરવામાં સરેરાશ સાત વર્ષ લાગી જાય છે તે ઉપરાંત, ઉપલબ્ધ હોય ત્યારે મોટાભાગની સારવાર ક્યાં તો ભારતમાં સુલભ હોતી નથી અથવા સરેરાશ ભારતીય દર્દીની પહોંચથી બહાર હોય છે.

અસાધારણ બિમારીઓ ભારત માટે ઓર્ગનાઇઝેશન (ઓઆરડીઆઈ) એ ભાગ્યે જ રોગના દર્દીઓ અને તેમના પરિવારોના પડકારો પ્રત્યે જાગૃતિ લાવવા માટે એક બિન-સ્પર્ધાત્મક રન 'રેસફોર્સ ૭' નું આયોજન કર્યું છે. પ્રતીકાત્મક રીતે રેસફોર્સ ૭ એ ૭૦૦૦ અસાધારણ રોગોનું પ્રતિનિધિત્વ કરે છે, જે અસાધારણ રોગોનું નિદાન કરવામાં સરેરાશ ૭ વર્ષ લે છે, તે વિશ્વમાં અસાધારણ રોગો માટેની તેની એક પ્રકારની ઘટના છે જેમાં ૭૦૦૦ લોકો દોડતા હોય છે અથવા ૭ કિલોમીટર ચાલે છે.



City ભાસ્કર

અમદાવાદ, રવિવાર, 1 માર્ચ, 2020

આજે સવારે 6.30
કલાક 7 કિ.મીની વોક
સિટી રિપોર્ટર | ઓર્ગનાઈઝેશન ફોર
રેર ડિસીઝ ઈન્ડિયા દ્વારા રેસફોર 7
દોડ અને વોક યોજવામાં આવશે જે
આજે સવારે 6.30 કલાકે ડેકાથલોન
એપલવૂડ ખાતે રહેશે જેમાં અસાધાર
રોગો પ્રત્યે જાગૃતિ લાવવાનો મેસેજ
પણ આપવામાં આવશે. આ ઈવેન્ટ
દેશના 20 શહેરોમાં પણ યોજાશે.

સંકે નવગુજરાત સમય

RNI Registration No. GUJGUJ/2014/55547 Year-7, Vol-09 Ahmedabad વિક્રમ સંવત ૨૦૭૬: ફાગણ સુદ છઠ | રવિવાર, ૧ માર્ચ, ૨૦૨૦ | ૧૨ + ૧૨ પાનાં રવિવાર સમય | કિંમત ₹૪.૦૦

અસાધારણ રોગો પ્રત્યે જાગૃતિ લાવવા આજે 'રેસફોર-7'

નવગુજરાત સમય > અમદાવાદ: ઓર્ગનાઈઝેશન ફોર રેર ડિસીઝ ઈન્ડિયા (ORDI) દ્વારા દેશભરમાં અનોખી નોન કોમ્પિટેટિવ રન 'રેસફોર 7' યોજાય છે. અસાધારણ થતા રોગોની જાગૃતિ માટે તેમજ પરિવારના આ રોગો સામેના પડકારો પ્રત્યે જાગૃતિ લાવવા માટે ઓરડીઆઈ દ્વારા અમદાવાદમાં 'રેસફોર 7' તારીખ 1 માર્ચ સવારે 6:30 વાગ્યે યોજાશે. આ દોડ ડેકાથલોન, અપલવૂડ, એસ.જી.હાઈવે પર શરૂ થશે.



Some more press coverages are given in the below links

<https://indiannewz.wordpress.com/2020/02/23/bangalore-runs-to-support-rare-disease-patients/>

<https://www.healthissuesindia.com/2020/02/26/rare-disease-children-race-for-awareness/>

<https://indiannewz.wordpress.com/2020/02/23/bangalore-runs-to-support-rare-disease-patients/>

<https://www.etvbharat.com/kannada/karnataka/state/bangaluru-urban/mp-tejaswi-surya-inaugurate-race-force-7-in-bangalore/ka20200223124030744>

<https://www.etvbharat.com/kannada/karnataka/state/bangaluru-urban/mp-tejaswi-surya-inaugurate-race-force-7-in-bangalore/ka20200223124030744>

<https://www.biospectrumindia.com/news/79/15830/ordi-organises-racefor7-to-raise-advocacy-for-rare-diseases.html>

<https://www.etvbharat.com/kannada/karnataka/state/bangaluru-urban/mp-tejaswi-surya-inaugurate-race-force-7-in-bangalore/ka20200223124030744>

<https://www.biovoicenews.com/ordi-to-hold-racefor7-to-raise-awareness-advocacy-for-rare-diseases/>



અસાધારણ રોગો પ્રત્યે જાગૃતિ લાવવા ઓઆરડીઆઈ દ્વારા અમદાવાદમાં 'રેસફોર્સ ૭' યોજાશે

ઓર્ગનાઈઝેશન ફોર રેર ડિઝીઝ ઈન્ડિયા (ORDI) દ્વારા દેશભરમાં અનોખી નોન કોમ્પિટેટીવ રન 'રેસફોર્સ ૭' યોજવામાં આવે છે. અસાધારણ થતા રોગોની જાગૃતિ માટે તેમજ પરિવારના આ રોગો સામેના પડકારો પ્રત્યે જાગૃતિ લાવવા માટે આ પ્રોગ્રામ આયોજિત કરાય છે. પ્રતિકાત્મક રીતે રેસફોર્સ ૭ દ્વારા ૭,૦૦૦ અસાધારણ રોગો સામે આવ્યા છે જે ઘણી મોટી વાત કહેવાય જેના કારણે અનેક લોકોમાં જાગૃતતા લાવવાના કાર્ય ઓરડીઆઈ દ્વારા કરાયું છે. જેથી આ કેમ્પેઈનને આગળ વધારવા માટે ૨૦૨૦ સુધીમાં

'રેસફોર્સ ૭' ભારતના ૨૦ શહેરોમાં યોજાઈ રહી છે જેની શરૂઆત ૭ ફેબ્રુઆરીથી થઈ ગઈ જે માર્ચ મહિના સુધી ચાલશે. આ કેમ્પેઈનમાં અત્યાર સુધી ૭,૦૦૦ લોકો જોડાયા છે જેઓ એક સાથે દોડ્યા હોય જે માટે ૭ કિલોમિટરની વોક યોજાય છે. આ કેમ્પેઈન અમદાવાદ, બેંગલુરુ, ચેન્નાઈ, કોઈમ્બતુર, દવાનાગર, દિલ્હી, હૈદરાબાદ, ઈન્દોર, જયપુર, કોચી, કોલકાતા, મેંગલુરુ મુંબઈ, મૈસુરુ, નાગપુર, પુડુચેરી, પુણે તેમજ તિરુવનંતપુરમ, વડોદરા અને વેલોરમાં યોજાશે. ગુજરાત ખાતે અમદાવાદમાં 'રેસફોર્સ ૭' તારીખ ૧

માર્ચના રોજ વહેલી સવારે ૬:૩૦ વાગ્યે યોજાશે, જે અપલબ્ડ્સ, એસ.જી. હાઈવે પર શરૂ થશે.

ઘણી બધી બિમારીઓ એવી છે, જેમાંની કેટલીક બિમારીઓ એવી છે કે જેના વિશે ડોક્ટરો પણ ઓછું જાણતા હોય છે અથવા જાણતા પણ નથી. આ જાગૃતિ દોડનો ઉદ્દેશ્ય એ છે કે સરકાર આ તરફ ધ્યાન આપે. આ અસાધારણ બીમારીઓનો સામનો કરી રહેલા બાળકો એ સાવચેતી રાખવી. જાગૃતિનો અભાવ અને ડાયગ્નોસ્ટિક્સના અભાવને કારણે કોઈ અસાધારણ રોગનું નિદાન કરવામાં સરેરાશ સાત વર્ષ લાગી જાય છે તે ઉપરાંત, ઉપલબ્ધ હોય ત્યારે મોટાભાગની સારવાર ક્યાં તો ભારતમાં સુલભ હોતી નથી અથવા સરેરાશ ભારતીય દર્દીની પહોંચથી બહાર હોય છે. અસાધારણ બિમારીઓ ભારત માટે ઓર્ગનાઈઝેશન (ઓઆરડીઆઈ) એ ભાગ્યે જ રોગના દર્દીઓ અને તેમના પરિવારોના પડકારો પ્રત્યે જાગૃતિ લાવવા માટે એક બિન-સ્પર્ધાત્મક રન 'રેસફોર્સ ૭' નું આયોજન કર્યું છે. પ્રતીકાત્મક રીતે રેસફોર્સ ૭ એ ૭૦૦૦ અસાધારણ રોગોનું પ્રતિનિધિત્વ કરે છે, જે અસાધારણ રોગોનું નિદાન કરવામાં સરેરાશ ૭ વર્ષ લે છે, તે વિશ્વમાં અસાધારણ રોગો માટેની તેની એક પ્રકારની ઘટના છે જેમાં ૭૦૦૦ લોકો દોડતા હોય છે અથવા ૭ કિલોમીટર ચાલે છે.

