



SAMPLE data collection sheet used for the vEDS project

Demographics and Family History

deID		
Sex		
Race		
Other Race		
Height (cm)		
Weight (kg)		
Age at diagnosis		
Method of Diagnosis		
COL3A1 gene mutation		
Protein Mutation		
Mother		
Describe		
Father		
Describe		
Sibling		
Describe		
Extended		
Describe		
Life Status		
Age Today		
Age at Death		
Cause of Death		
Autopsy performed		
Autopsy findings		

Clinical Criteria

Easy Bruising		
Arterial, Intestinal, or Uterine fragility		
Thin, translucent skin		
Characteristic facial features		
Small joint hypermobility		
Skin hyperextensibility		
Spontaneous pneumothorax/hemothorax		
Tendon or muscle rupture		
Early-onset varicose veins		
Talipes equinovarus (clubfoot)		
Carotid-cavernous fistula		
Describe Other		

Comorbidities

Smoking History		
Hypertension		
Hyperlipidemia		
Diabetes Mellitus		
Previous MI		
Coronary Artery Disease		
Stroke		
TIA		
Polycystic Ovarian Syndrome		
Deep Vein Thrombosis		
Pulmonary Embolism		
Other Comorbidities		

Pregnancy and/or GI complications

Gravida		
Parity		
Spontaneous Abortions		
Termination of Pregnancy		
Living Children		
Diagnosis in relation to pregnancy		
Pregnancy Complications		
Describe		
GI Involvement		
Type of Initial GI presentation		
Known Diagnosis at Time of First GI Presentation		
Age at time of Initial GI Presentation		
Describe GI Involvement		

Pneumothorax/Hemothorax

Pneumothorax (PTX)		
Age at time of first PTX		
Known diagnosis at time of first PTX		
Hospital Length of Stay		
Management		
Recurrent PTX		
Management		
Complications		
Hemothorax (HTX)		
Age at time of first HTX		
Known diagnosis at time of first HTX		
Hospital Length of Stay		
Management		
Recurrent HTX		
Management		
Complications		

Thoracic Aortic Surgery (fill out surgical details below)		
Abdominal Aortic Surgery (fill out surgical details below)		

Vascular Presentation 1

Type of Initial Vascular Presentation		
Known Diagnosis at Time of First Vascular Presentation		
Age at time of Initial Vascular Presentation		
Arterial Involvement		
Type		
Other		
Arterial Involvement		
Type		
Other		
Arterial Involvement		
Type		
Other		
Arterial Involvement		
Type		
Other		

Surgery 1

Vascular procedure type		
Endo Procedure Type		
Indication for Procedure		
Access		
Largest Sheath Inserted		
Closure Method		
Cell Saver used		
Cell Saver Quantity used		
Blood Transfusion		
PRBC Quantity		
FFP Quantity		
Platelets Quantity		
Cryo Quantity		
Fibrinogen Quantity		
Percutaneous Access Site Complications		
Comments		
Wound Complications		
Management of Wound Complications		
Abdominal Wound Dehiscence		
Describe		
In Hospital Mortality		
Mechanical Ventilation >24 hours		

Days on Mechanical Ventilation		
Pneumonia		
Stroke		
Details		
ARF		
Need HD		
Resolved		
DVT		
MI		
Troponin Leak		
A-Fib		
OR Takeback		
Describe		
Total days in hospital		
Days in ICU		
Discharged to		
Readmission		
Describe		

Notable challenges with tissue		
Additional comments		